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ABSTRACT

This document provides testimony from two Congressional hearings, one on the subject of long-term care services for the elderly and the other on Alzheimer's disease and related disorders. In the hearing on long-term care, opening remarks are given by Congressmen Waxman and Wyden. Expert testimony from the following witnesses is provided: (1) Marie-Louise Ansak, executive director of On-Lok Senior Health Services; (2) Karen Davis, professor and chairman, Department of Health Policy and Management, Johns Hopkins University; (3) Judith Feder, co-director, Center for Health Policy Studies, Georgetown University; (4) Lloyd W. Lewis, executive director, Kendal-Crosslands; (5) Teri L. Louden, president, Louden & Co., and (6) John W. Rowe, director, Division of Aging, Harvard Medical School. In the hearing on Alzheimer's disease, opening remarks or statements are given by Congressmen Waxman, Roybal, Pepper, and Bilirakis. The testimony of 18 witnesses, comprising more than 100 pages is given. These witnesses include academic and service program experts, relatives of Alzheimer's victims, and other concerned persons. (ABL)

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PROBLEMS AND ISSUES IN LONG-TERM CARE

HEARINGS

BEFORE THE

SUBCOMMITTEE ON
HEALTH AND THE ENVIRONMENT

OF THE

COMMITTEE ON ENERGY AND COMMERCE
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

LONG-TERM CARE SERVICES FOR THE ELDERLY
OCTOBER 18, 1985

ALZHEIMER'S DISEASE AND RELATED DISORDERS
JANUARY 27, 1986

Serial No. 99-71

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LONG-TERM CARE SERVICES FOR THE ELDERLY

FRIDAY, OCTOBER 18, 1985

House of Representatives,
Committee on Energy and Commerce,
Subcommittee on Health and the Environment,
Washington, DC.

The subcommittee met, pursuant to call at 9:50 a.m., in room 2322, Rayburn House Office Building, Hon. Henry A. Waxman (chairman) presiding.

Mr. **Waxman**. The meeting of the subcommittee will come to order. Today's hearings are on long-term care services for the elderly. They mark the beginning of the subcommittee's review of existing long-term programs, and its search for new approaches.

For years now, we in Congress have heard the pleas of the Nation's elderly and their families.

Medicare reimburses for only very limited nursing home care and community-based services. Compensation for services relating to conditions such as Alzheimer's disease is nonexistent.

Medicaid requires impoverishment before any long-term care services will be paid for. Even then, most coverage is for institutional services.

Private initiatives such as life care communities are available only to those with the greatest wealth and not necessarily to those with the greatest need.

The long-term care problems older Americans and their families face are difficult and confusing. As a result, their message to us is always simple and clear: the system is not working. It's not working for those who need services. It's not working for their families who try to provide services. And it's not working for Federal and State Governments that pay for services.

These people are right. And Washington policymakers know they are right. Today's so-called long-term care system is misguided, misused, misfunded, and misunderstood.

So for years now, we in Congress have also heard the promises of this administration and some of our fellow Members. They acknowledge Americans need something better. They know Americans want something better. And they promise Americans will have something better . . . sometime in the future.

But the future is now. Current statistics and projections make that clear:

Today, there are over 1 million elderly residing in nursing homes. This number may double by the year 2000.

For every person 65 years of age and older living in an institution, there are two others requiring similar levels of care living in the community.

Nursing home services for the elderly now account for one-third of all Medicaid spending. This share will undoubtedly grow as the number of needy aged swells.

On average, an elderly nursing home resident pays $18,000 a year for privately financed long-term care services. This figure does not even include the cost of drugs or cost sharing for physician visits and other services.

Yes; the future is now. And the time to develop a new comprehensive long-term care program is also now.

It won't be easy and it won't be free. But when I look in the faces of families struggling to care for an aging parent or trying to maintain an Alzheimer's victim at home, I am firmly convinced that Americans are ready and willing to make the necessary commitment.

So we begin this process today by learning about long-term care problems and programs that already exist. We will learn about long-term care medicine and long-term care economics. We will learn about long-term care financing in both the public and private sector. And we will learn about promising models for delivering and financing long-term care services in the future.

There is much to learn and much to do. I look forward to working with my colleagues on a long-term initiative, and I hope, to seeing our older Americans receiving the kind of care they have so long deserved.

Before I recognize other members for their opening statements, I want to note the long-term care background report that was prepared by the Congressional Research Service for this hearing. The report contains an indepth analysis of various issues concerning long-term care. This information will undoubtedly be most helpful to members and their staffs as our discussions on a comprehensive long-term care program progress. Without objection, then, I would ask that a copy of the CRS report entitled, "Financing and Delivery of Long-Term Care Services for the Elderly", be included in today's hearing record.

[The report appears on p. 184.]

I am now going to call on our colleague, Congressman Ron Wyden, who has been a clear leader in this area, who has shown a great deal of interest, and who in fact, began his career even before coming to Congress in the area of health and elderly. Clearly our concerns for the elderly have to be in terms of their long-term care needs as well as with Medicare.

I have been looking forward to this hearing for a long time. We had trouble scheduling it because it has been difficult to match the schedules of the members of the committee, and the witnesses that are here today. I am going to have to apologize, because unfortunately we have before us something that shouldn't be before us, and that is the Gramm-Rudman proposal.

It is, as this group certainly knows, as severe a threat to the elderly in this Nation and others who rely on Government services as any that we have had in the last 5 years. The Congress is in a conference committee of the House and the Senate, and the conference committee now is to look at this Gramm-Rudman proposal. If I had my say, I wouldn't have scheduled it at the same time as this hearing. It is scheduled to begin at 10 o'clock. So I am going to call on Congressman Wyden to not only make any comments he wishes to make, but to take over the chair.

I am going to look forward to reviewing the record, Mr. Wyden, and to working with you and the other witnesses and others that will be interested in this whole area, as we pursue legislation along these lines. I think we have neglected the subject for too long.

I think we have acted as if the long-term care needs of this Nation could be handled without commitment of additional funds and without revising the programs that are now in existence. And I think we have to make it very clear, those of us who are involved in policymaking, that we just can't think that this problem of the aging will go away without an active Federal Government intervention.

Thank you very much, Mr. Wyden.

Mr. WYDEN. Mr. Chairman, I have my own statement. But before you leave, I want to tell you how much I appreciate your advocacy for low-income seniors. In your absence we will try to build an excellent record. When you are able to lead us again, after the fight to protect low-income seniors is won, you will have the kind of record your subcommittee can use to develop a good long-term care initiative for older people.

We appreciate all your advocacy for seniors and your assistance.

Mr. WAXMAN. Thank you very much.

Mr. WYDEN. In Chairman Waxman's absence, we will have to make do.

I just have a very short opening statement of my own. I wanted to say that I recently saw the movie, "Cocoon." Art and Ben, two very spirited senior citizens, seemed to really have it all figured out. While earthlings have to wring their hands over wallet-busting health care bills, Art and Ben let themselves be whisked away from their retirement home on a spaceship with some aliens for a promise of perpetual life, and no bill collectors.

I am sure a number of people saw the movie. I thought it was just terrific science fiction. Unfortunately most of our senior citizens in this country can expect no such relief from their nursing home bills. Here on Earth millions of senior citizens and their families face a shocking and a shabby deal. It is the pain that many are going to reap as they enter their seventies and eighties. They will come to need long-term health care, only to learn, and too late, that no such affordable care exists in this country. What we know is that most older people don't see the cyclone coming.

We know that almost 80 percent of older people now believe that Medicare is going to pay their nursing home costs. The fact of the matter is that is not correct. That Medicare is going to pay these nursing home bills for older people is really a very very tragic misconception. As we are going to learn today, it doesn't.

It pays very few of them. Too late three out of four older people discover that to qualify for Medicare they must first be hospitalized for a major illness or injury before getting transferred to a nursing care facility for which Medicare will pay. Too late do their children discover that Medicare isn't going to pay for most nursing home bills. And too late, as Chairman Waxman has mentioned, do governments and taxpayers understand the steep dollar and societal costs.

We have got more than 1 million older people living in nursing homes today, at a cost of $15,000 to $30,000 annually. Medicare is paying for about 1 percent of our nursing home population. Private insurance chips in another 1 percent. And Medicaid pays a large portion of the bill.

That has been 45 percent. And families must come up with the rest of the $15,000 to $30,000 annually. These figures are grim, icy numerals that go beyond ravaging the lifetime savings of middle- and working-class people. It is impoverishing them.

We have heard about what it takes to be a "successful Medicaid recipient." Even they pay a staggering price. One-half of all Medicaid nursing home patients initially were not poor. They weren't poor at the beginning. They were teachers and farmers and professional people. Medicaid demanded that they become poor. Eventually when they spent down all their assets, they could meet Medicaid's draconian destitution requirements. Very few of our older people and their families are pleased with the tradeoff of becoming impoverished just to have some measure of health care.

I think very few Americans expect that the U.S. Treasury can pay all the future costs of long-term care. With the $2 trillion Federal debt that is now a reality, that isn't cards. It seems to me that what we are about at this hearing, is to try to develop a national strategy to meet the long-term care needs of our proud and often very able older people. What we need is a national strategy that includes ways to come up with adequate long-term health care without impoverishing the families of this country.

The last point that I would mention is that I don't think one solution is going to do. I think we are going to need a variety of solutions. I think we are going to need innovative experiments, folks. We have got a very good one in my community in Portland. The Kaiser Social Health Maintenance Organization, helped by the leadership of Mitch Greenlick, is exactly the kind of innovative experiment that we are going to need. Also, I think we are going to need better programs to get out consumer information, so that older people can really find out what their rights are and so that we don't have 80 percent of them thinking that Medicare is going to pay nursing home bills, when it covers virtually none.

I think we are also going to have to have better targeting of Government resources, so that, when we have such limited resources, we can concentrate on the most efficient approaches to get help to low-income older people. And I think we are also going to need private sector energy and innovation.

This last point, I think, is really the unheralded key, really the missing piece of the puzzle. I have produced legislation that I think would dramatically speed up the time when comprehensive private insurance for long-term care was available for older people and their families in this country.

Chairman Waxman has included my bill in the reconciliation package that goes to the House floor. The point of the bill is to give guidelines to both the industry and consumers about what long-term care insurance ought to look like, and how to speed up its delivery to American families. It uses the National Association of Insurance Commissioners and their expertise as the focal point. I think we can get that bill passed in this Congress and speed up the availability of private long-term care insurance for those older people and their families who can afford it.

Not all can afford it today. No one has contended that private long-term care insurance is more than but a piece of the puzzle. But it is an important piece. As we start to eliminate age discrimination in this country and more older people have a chance to work and get better pensions, I think more of them are going to be able to take advantage of private long-term care insurance.

We are going to look at all these strategies today. We welcome our witnesses. I think the point of the hearing is clear, to build a good hearing record for the committee, and Chairman Waxman, so that we can have a long-term care initiative in this Congress. I very much look forward to hearing our witnesses today.

Our first panel today will provide us with information on the medical, demographic, and economic aspects of long-term care. We are happy to have Dr. John W. Rowe, a physician with the Division of Aging at Harvard Medical School, and Dr. Karen Davis, who chairs the Department of Health Policy and Management at the Johns Hopkins School of Hygiene and Public Health.

We are happy to have both our witnesses. Both have been involved with the elderly for many many, years, and are nationally known for their work in long-term care policies. We thank both of you for your participation in the hearing. We have already received copies, Dr. Davis and Dr. Rowe, of your prepared testimony, which we will include in our record in full.

What we would like this morning is to have you summarize your remarks in no more than 5 minutes. We have got a very lengthy schedule today, and I know the subcommittee has a number of questions for both of you. Let us begin with you, Dr. Rowe. If you could just highlight your central concerns for us today, that would be very helpful.

STATEMENTS OF JOHN W. ROWE, M.D., DIRECTOR, DIVISION ON AGING, HARVARD MEDICAL SCHOOL; AND KAREN DAVIS, PROFESSOR AND CHAIRMAN, DEPARTMENT OF HEALTH POLICY AND MANAGEMENT, SCHOOL OF HYGIENE AND PUBIC HEALTH, JOHNS HOPKINS UNIVERSITY

Dr. Rowe. Thank you, Mr. Wyden. I am Jack Rowe, director of the Division on Aging at Harvard Medical School. I am a physician interested in the care of the elderly.

This morning, I would like to make one major point: that dramatic difference in the health status, health care needs, and the health care utilization between young and old individuals are not purely quantitative, but are also qualitative.

There are important qualitative differences that need to be considered as plans are made for the changes you mentioned, in the structure and financing of our health care system for the elderly.

The challenge before us is coupling the recent increase in lifespan with similar increases in health span. It was once assumed that increase in longevity would ordinarily bring prolongation of vitality and compression of morbidity until the very end of life.

This claim has recently been challenged, and it is now not clear at all that what we will not have is previously unimagined numbers of elderly individuals living long periods of dependency in their late life.

With advancing age, there is a well-known increase in the prevalence of a wide variety of diseases. Some of these diseases occur in all adult age groups, but just more frequently in the elderly, such as high blood pressure, which is 50 percent more common in the elderly than in younger individuals. Disorders of arteries, hearing disorders, and heart disease are twice as common. Vision impairment is three times as common.

Other diseases occur almost exclusively in the elderly, and of these the most important which you mentioned in your introductory comments is Alzheimer's disease which currently has 2 million victims. It is expected that by the end of this century there may be 4 million elderly victims of Alzheimer's disease. In addition, there are a number of disabling geriatric syndromes which occur solely in the elderly, and which are not listed as diagnoses. These include urinary incontinence, falling, fainting, weight loss, and nutritional impairment. While the accumulation of diagnoses with advancing age is important, it is a principle of geriatrics that diagnosis is an inadequate criterion by which to judge the health care needs of the elderly, the emphasis should be on the functional impact of a given diagnosis.

I could give you an example of a 75-year-old man with diabetes, hypertension, and arthritis, who had suffered a heart attack who is effectively practicing law or medicine or perhaps serving on this committee in Congress. I could give you an example of a similar 75-year-old man with the same diagnoses who is markedly disabled in a nursing home.

That diagnosis by itself is not adequate in the elderly is also underlined by the fact that between the ages of 55 and 65, the number of individuals, with high blood pressure that have disability from that disease triples, and similar trends are seen with other diseases. So it is not purely the diagnosis, but its functional impact.

A substantial portion of older Americans living in the community report major functional limitations due to chronic diseases, and require long-term assistance. Fourteen percent of individuals age 75 require assistance in their activities of daily living, a figure that rises to 40 percent over age 80.

The impact of these changes is increased even more by the dramatic increase in the number of individuals over age 80. Even if you make it to old age fully independent, you are in trouble. A fully independent 65-year-old has a life expectancy of 17 years, and will spend 6½ of those years requiring assistance for major activities of daily living.

There are several important characteristics of the elderly which limit the capacity of our current health care system to deal with them. First of all, they underreport illness. They fail to seek assistance. The symptoms that they come with are just the tip of the treatable iceberg, and when this underreporting of illnesses is coupled with the fact that their symptoms are often different than in younger individuals, it becomes clear that diseases in the elderly are often more far advanced, more difficult to treat, and carry a worse prognosis.

These characteristics of nonreporting and altered presentation are especially dangerous in the American Health Care System, which is passive, and which lacks prevention-oriented or early detection efforts.

I think it is particularly important to recognize that the health care of the elderly is not limited to the provision of long-term care services. Currently 40 percent of health expenditures for the elderly are in the acute care sector. This has often been neglected. People equate geriatrics with long-term care. That is a mistake.

Another mistake is to equate the focus of care with the type of care being provided. Many patients in acute care settings are really being given long-term care. Similarly, with prospective payment, we are increasingly seeing patients admitted to nursing homes who require acute care. They seem to go from the operating room to the recovery room to the nursing home. Hospitals are interested in dumping the patients as quickly as possible, and the long-term care facilities are not designed, they are not staffed and they are certainly not reimbursed to provide acute care services.

To conclude, I would like to mention just one important subgroup of the elderly, and that is the elderly veteran. By the end of this century, 60 percent of the elderly men in this country will be eligible for health care benefits under Medicare, and unless the eligibility rules are changed, also eligible for health care benefits from the Veterans Administration. Increasing costs in one sector will initially drive these patients with dual eligibility to the less restrictive or less expensive option, and in view of the tendency for Federal agencies to resist coordination with other Federal agencies, in order to protect their own turf and budget, it is highly likely that we are going to have a major problem unless Congress directs some coordination.

I can clearly see that increases in copayments and deductibles in Medicare will drive men into the VA system. The VA system will be overwhelmed, and will therefore increase the eligibility requirements which will drive men back to Medicare, and this fiasco, which I think is not improbable, can be prevented by congressional action.

This concludes my remarks. I appreciate the opportunity to appear before you this morning. I would be pleased to answer any questions.

[The prepared statement of Dr. Rowe follows:]

Testimony before the U.S. House of Representatives
Committee on Energy and Commerce
Subcommittee on Health and the Environment

October 18, 1985

Mr. Chairman, I am John W. Rowe, Director of the Division on Aging at Harvard Medical School. I am a physician with particular interest in the health care of the elderly and the health policy implications of our rapidly growing geriatrics population. This morning I would like to make two major points. First, that the health status, health care needs and health care utilization of elderly individuals are very different from that of their younger counterparts, and, second that these differences are not purely quantitative, but there are important qualitative differences that need to be considered as plans are made for changes in the structure and financing of our health care system. Just as children are not merely young versions of adults the elderly are not simply old adults - they present special challenges and require special approaches.

The challenge before us is coupling the recent increases in longevity with similar increases in well being. Now that there have been remarkable increases in life span, our task is to lengthen health span. It was once assumed that increases in longevity would naturally be associated with prolongation of vitality and compression of morbidity until the very end of the life span. However, this claim has recently been challenged by studies suggesting that the increased life span of the oldest old is not accompanied by decreased morbidity and may actually result in prolongation of the period of dependency and more dramatic increases in the need for health care.

With advancing age there is a well known increase in the prevalence of a wide variety of diseases. Some diseases occur in all adult age groups though more frequently in the elderly. Comparing individuals age 45 to 64 with those over age 64, hypertension becomes 50 percent more common, the prevalence of arthritis, hearing disorders, heart disease and urinary abnormalities doubles and the prevalence of vision impairment almost triples. Some diseases occur almost exclusively in the elderly, of these the most prevalent and most important in terms of its devastating effects on function and the strain on the financing of the health care system is senile dementia with approximately two million victims currently. In addition, there are a number of important "geriatric syndromes" which occur almost solely in the geriatric population and which are often not listed specifically as diagnoses. These include urinary incontinence, falling, fainting, weight loss, nutritional impairment, and "failure to thrive".

It is a principle of geriatric medicine, that diagnosis is a very poor criterion to judge the health care needs of the elderly. When dealing with elderly individuals, the emphasis should be on the functional capability and not solely on the diagnosis. Although a complete and precise diagnosis is essential, the functional impact of each diagnosis should be evaluated. Specific diagnoses often have little relation of functional status and the length of the diagnosis list provides little insight into the specific needs of an elderly patient. This is emphasized by the fact that I could present to you a 75 year old man with diabetes, hypertension, a previous heart attack and arthritis who was in fact effectively practicing law, or medicine, or serving in Congress. Whereas another 75 year old man with the same diagnoses might be severely disabled and residing in a nursing home. The importance of considering the functional impact of a diagnosis, rather than purely the diagnosis, is also evident in the fact that of individuals between age 55 and 64 with hypertension, 27 percent have a disability related to that condition, a figure which rises to 72 percent of the individuals with hypertension over age 75. Similar, trends are also present for a number of other chronic conditions. The obvious weakness of diagnosis as a criterion for utilization of health services in the elderly underlies the concern of geriatric practitioners regarding the impact and utility of diagnosis related groups as a yardstick for prospective payment.

While most older Americans living in the community are cognitively intact and fully independent in their daily activities, a substantial portion report major activity limitations due to chronic conditions. This effect is markedly age related rising from 14 percent of individuals age 75 who require assistance in their basic activities of daily living to approximately 40 percent over age 80. Even if one maintains functional independence into old age, the risk of becoming frail for a prolonged period is still high. For independent persons between the ages of 65 and 69 years, total life expectancy is 16.5 years but, active life expendency or the portion of the remaining years characterize by independence is only ten years, and the remaining six and a half years is characterized by major functional impairment.

There are several important aspects of the interaction of ill elderly with the heath care system which have a major impact on their health care utilization. An important contributor to functional impairment in the elderly is their failure to seek assistance. Studies in several countries with varying health care systems indicate that symptoms of serious and treatable diseases often go unreported. Health problems reported by frail elderly persons are frequently only the tip of the iceberg of treatable illness. When this underreporting of illness is coupled with the fundamental principle of geriatric medicine that signs and symptoms of disease in the elderly often differ from those of their younger counter-parts, it is clear why elderly individuals often are found to have advanced disease that is more difficult to treat and carry a worse prognosis. These characteristics of nonreporting and altered presentation of disease are especially dangerous when coupled with the passive organizational structure of American health care delivery which lacks prevention oriented or early detection efforts.

Another important characteristic of the elderly is multiple pathology. The coexistence of several diseases has a profoundly negative influence on health and functional independence in the elderly. Elderly persons living in the community have 3.5 important disabilities per person and the hospitalized elderly have evidence of six pathologic conditions per person.

It is particularly important to recognize that health care of the elderly is not limited to the provision of long-term care services. The dramatic projected increases in the amount and costs of long-term care over the next couple decades has led to a preoccupation of the federal government with the nursing home patient. We are progressively overlooking the fact that elderly individuals consume a very substantial portion of the acute care services with approximately 40 percent of health care expenditures in the over 65 age group being devoted to acute care. While the portion of individuals in nursing homes rises very dramatically with age, from two percent between age 65 and 74 to 25 percent of age 85, it is also important to recognize that acute hospital days double between age 70 and age 85 in the elderly.

It is also important not to equate the locus of care with the type of care being provided. Many individuals awaiting nursing home placement are essentially being provided long-term care services in the acute care setting. Similarly, with prospective payment patients are being transferred from acute care hospitals to long-term care facilities much sooner than previously, thus requiring acute care services in the long-term care setting. This is placing a special burden on the already over burdened long-term care sector since these facilities are often not designed and the staff not properly trained to provide the acute care services their patients require.

An important subgroup of the elderly that deserves special note is the older veteran. The number of older veterans is increasing very, very rapidly and will bring a markedly increased demand for health care. By the year 2000, 60 percent of the elderly men in this country will be eligible for health benefits from the veterans administration if there is no major change in eligibility. It is important to recognize that there is a dual eligibility among older veterans. While all veterans over age 65 are currently eligible for VA health care 81 percent of these also qualify for medicare. Our studies indicate that changes in one portion of the health care system for the older veteran will have a dramatic effect on other portions of the system. Increasing costs in one sector will naturally drive patients with dual eligibility to less restrictive or less expensive option. In view of the need to reduce the deficit and the tendency for federal agencies to resist coordination with other federal agencies in order to protect their own turf, congressional action is needed to stimulate the VA and other federal agencies to coordinate funding and share clinical resources for the benefit of older veterans and all older patients.

This concludes my remarks. I appreciate the opportunity to appear before this Committee and would be pleased to answer any questions. Thank you very much.

Mr. WYDEN. Dr. Davis.

STATEMENT OF KAREN DAVIS

Ms. DAVIS. Thank you for the opportunity to testify before this committee on the economic implications of an aging population.

Aging of the population in the United States is one of the major public policy issues facing this country. The proportion of Americans age 65 and over will increase from 11 percent or 26 million Americans in 1980 to over 20 percent of the population, or about 60 million people by the year 2030.

The prevalence of chronic health conditions, disability, and frailty in society will increase, along with the demand for health and long-term care services. Financing these services will cause major strains on the elderly—especially vulnerable groups such as the poor and near-poor, those who are frail or chronically ill, and those who live alone without adequate support from families and communities.

In 1984, the United States spent $120 billion on personal health care services to the elderly. Medicare, Medicaid, and other public programs picked up $81 billion or about two-thirds of these expenditures, while private payments including $30 billion of direct out-of-pocket payments and $9 billion of private insurance payments accounted for the remainder.

On a per capita basis, the United States spent $4,200 on health services in 1984 per elderly person. Public programs around private insurance plans pick up a portion of these expenses, but this varies by type of service. In the case of hospital care, public programs and private insurance plans pick up nearly all of the total.

In the case of physicians' services, public programs pick up about 60 percent, and private health insurance, picks up 14 percent, leaving about a fourth of those expenses to be paid directly by the elderly. But in the case of nursing home care, about half of these payments are made privately by those elderly in nursing homes.

These gaps in coverage under public programs and private insurance plans create four major problems for the elderly population. First, it is the gap in acute care benefits; second, particular problems for the near-poor elderly; third, the absence of financial protection for nursing home care; and, fourth, inadequate long-term care services at home, especially for the elderly living alone.

Rather than giving you a lot of numbers on these, I would like to highlight each of these problems with a typical case. First, turning to the gaps in acute care benefits, take the case of an elderly woman with an average income for an elderly person, about $10,000. Suppose this woman is especially sick, has a chronic condition that requires two hospital episodes during the year. She would pay $400 each time she went to the hospital, a total of $800.

She would also pay $75, the deductible for her physician services. She would pay her Medicare premium for physician services, another $180. Through these two hospital episodes and before and after those episodes in going to the physician, she incurred total physician bills where her coinsurance, 20-percent requirement was another $1,000.

In addition she has prescription drugs that aren't paid for by Medicare, and she has to pay $40 a month for these expenses, another $600 a year. Those expenses just from two hospital episodes, the physician services, her premiums, her prescription drugs, come to over $2,600 a year. So for this woman making $10,000 a year, this is over one-fourth of her income that must go to meet her out-of-pocket expenses, even though she has Medicare coverage.

The second problem is that of the near-poor elderly. Take the case of a woman with $5,000 in income who is not as sick as the first woman we discussed, but she does have one hospital episode during the year, some physician bills, some prescription drug bills. She pays her $200 Medicare premium. She has got $1,000 to $1,500 of medical expenses, again, over 20 percent of her income with a total income of $5,000.

She is a little bit high to be covered by the Medicaid Program, so she must pay all of these expenses that Medicare doesn't cover directly out of pocket. Let's take the third case, that of a couple, where the woman has Alzheimer's disease, and is placed in a nursing home. And the man is frail at home, having difficulty taking care of himself. Together they have an income of $15,000 a year, and some assets.

They are ineligible for Medicaid, but yet her nursing home bills average, as you said, $16,000 a year, so that consumes all of their income, cuts into their savings, before they start paying the bills that he has to pay at home for his own medical bills, food, and other daily expenses. The final case I would like to turn to is that of an elderly woman over 85 years in age living at home. She is having difficulty shopping, maybe has limited vision, limited ability to get around, needs someone to come in, bring her food, perhaps do some cooking.

If she has a condition like diabetes, she may need some nursing services in her home with her medications. She doesn't know where to turn to get this kind of assistance. Many of these services that she needs are not clearly available in the community, and there are no programs since she doesn't qualify for Medicaid that would assist her in financing these services.

Those are the four major medical problems we face in this country. With regard to the economic resources of the aged, it has become fashionable to say that the elderly are rich enough to pay for their own Medicare bills. This analysis, I think, is misleading for several reasons. These comparisons, first of all, don't look at the out-of-pocket expenses of the elderly which are much higher, even with Medicare and Medicaid, than for the nonelderly.

The elderly spend privately over $1,000 for their medical expense. There is about $300 spent out of pocket by the nonelderly for their medical expenses, so more than $700 or $750 more for the elderly than the nonelderly.

In addition when these comparisons are made between th elderly and the nonelderly, they tend to focus on per capita income. That means they say that economic resources of supporting a child are the same as supporting that of an elderly woman living alone. In fact, if you look at household incomes, then you will see that those are much lower for the elderly, but the main point is not what is true of the elderly as a group versus the young as a group.

It is looking at subgroups who have problems whether they are old or younger, and it is those subgroups of poor and near-poor elderly, the frail, the chronically ill, those in nursing homes, that I think we need to address public policies.

I would urge the Congress to take several steps to deal with these inadequacies in current health and long-term care benefits for elderly people. These include: expansion of Medicare acute care benefits to include, for example, prescription drugs and catastrophic expenses; improved protection for the near-poor elderly, such as expanding the eligibility of near-poor elderly for buy-in to Medicare through the Medicaid Program; addition of long-term care coverage as an optional Medicare benefit financed by an income-related premium; expansion of long-term care services to include a broader range of community-based services and a central focal point in communities for information and referral to long-term care providers.

In the debate over long-term care, it should not be forgotten that Medicare, Medicaid, and other public programs are essential to assuring that many of our Nation's most vulnerable citizens can live out their lives with dignity, freed of the worry of financial ruin that major illness can bring. Current fiscal problems should not cause us to lose sight of the major steps that need to be taken to improve, rather than dismantle, these programs. Thank you.

[Testimony resumes on p. 24.]

[The prepared statement of Ms. Davis follows:]

ECONOMIC IMPLICATIONS OF PROVIDING HEALTH AND LONG-TERM CARE TO AN AGING POPULATION

Karen Davis

Thank you, Mr. Chairman, for this opportunity to testify before the Committee on the economic implications of an aging population. Aging of the population in the U.S. is one of the major public policy issues facing this country. The proportion of Americans age 65 and over will increase from 11 percent or 26 million people in 1980 to over 20 percent or about 60 million people by the year 2030. ✓The prevalence of chronic health conditions, disability, and fraility in society will increase, along with the demand for health and long-term care services. Financing these services will cause major strains on the elderly -- especially vulnerable groups such as the poor and near-poor, those who are frail or chronically ill, and those who live alone without adequate support from families and communities./ It will also cause a major fiscal problem for the Medicare and Medicaid programs. The public policy challenge is to prepare for the aging of the population by taking steps now to improve the adequacy of Medicare, Medicaid, and other health and long-term care programs.

Today, I would like to summarize for the Committee what we know about the inadequacies in health and long term care benefits for the elderly in current programs, indicate the hardship this causes for the elderly, highlight the needs of especially vulnerable segments of the elderly population, and review the financial resources of the elderly that are available to meet their health and long-term care needs. I would like to conclude with some suggestions on reform strategies that would assist our growing elderly population.

Financing Health Services for an Aging Population

In 1984, the U.S. spent $120 billion on personal health care services to the elderly. Medicare, Medicaid, and other public programs picked up $81 billion or about two-thirds of these expenditures, while private payments including $30 billion of direct out-of-pocket payments and $9 billion of private insurance payments accounted for the remainder.

On a per capita basis, the U.S. spent $4,200 on health services in 1984 per elderly person. Medicare paid slightly less than half of this amount ($2,050); Medicaid contributed 13 percent (or $540); the elderly paid one-fourth of the total directly through out-of-pocket expenses ($1,060), with the remaining expenses met by other public programs and private plans. These are clearly large sums of money representing significant proportions of the income of the elderly and of the budgets of federal and state governments. On average, the elderly devoted 15 percent of their income to health care expenses in 1984, up from 12 percent in 1977.

The distribution of financing health services varies by type of service. Public programs pick up 89 percent of the hospital expenses of the elderly, 60 percent of the physician expenses, but only 48 percent of the nursing home expenses of the elderly. Private health insurance picks up 8 percent of all hospital expenses of the elderly, 14 percent of the physician expenses, but only 1 percent of all nursing home expenses.

Among the 1.3 million elderly people in nursing homes, about half are covered by Medicaid although more will exhaust their financial resources and eventually become eligible for Medicaid. For the half not covered by Medicaid, private out-of-pocket expenses came to $12.6 billion in 1984, or about $20,000 per person. For those frail elderly requiring years of nursing home care at the end of life, the financial hardship can be catastrophic.

Those elderly not in nursing homes can also incur substantial private expenses. The hospital deductible for Medicare has increased from $204 in 1981 to $400 in 1985. For elderly with very long hospital stays, Medicare benefits can be exhausted. The elderly are required to pay one-fourth of the deductible (or $100 in 1985) for each day of care between the 60th and 90th day of hospital care in a given episode of illness, and one-half of that amount for each day of care in a 90 day lifetime reserve. Once these days of hospital care have been exhausted the elderly must pay all of their hospital expenses.

The elderly incur especially heavy costs for physician services. The elderly pay the first $75 of physician bills during the year, 20 percent of Medicare allowed physician fees above that deductible amount, and the excess of all charges physicians make above the Medicare allowable fee. These charges can quickly become an enormous burden on the elderly. For this physician coverage, the elderly must pay a premium. The premium for physician services in 1985 was $15.50 per month, up from $11.00 in 1981.

Prescription drugs, dental care, eyeglasses, hearing aids, and many other health services essential to daily living are excluded from Medicare coverage and represent major costs to those elderly requiring these services.

Medicare payments are concentrated on those sickest elderly. About 6 percent of Medicare aged beneficiaries account for 61 percent of all Medicare reimbursements for the aged. About 40 percent of Medicare beneficiaries do not receive reimbursement from Medicare, and another 36 percent incur less than $500 in Medicare reimbursed services.

Despite important assistance from Medicare, the sickest elderly also face the most significant financial burdens. In 1980, 10 percent of the elderly accounted for almost half of the private outlays (or cost-sharing amounts) for Medicare benefits with personal liability of more than $500 for Medicare benefits. In addition many of these same individuals have substantial outlays for noncovered benefits such as prescription drugs.

Out-of-pocket medical expenses are a particular burden for those elderly who do not have supplementary coverage to Medicare -- either from Medicaid or private health insurance. Medicaid picks up Medicare's cost-sharing requirements and many other essential health care services for 3.5 million poor elderly. But over 8 million the elderly have family incomes below $10,000 and find the gaps in Medicare difficult to meet.

The heavy financial burden on lower income elderly is in part a reflection of their inability to afford supplementary private health insurance to fill in the gaps left by Medicare. Overall, 66 percent of the elderly have private health insurance in addition to Medicare. However, this varies widely by income. Of those poor or near poor elderly, 47 percent have private insurance compared with 78 percent of the high-income elderly.

Even those with supplementary coverage can experience quite burdensome medical expenses if they are seriously ill. For elderly of all incomes with health care bills exceeding $2,500 in 1977, those with Medicare alone spent 37 percent of their income on health care, those with both Medicare and Medicaid spent 9 percent of their income on health care, and those with Medicare and private insurance spent 18 percent of their income on health bills. For the poor and near-poor elderly households with total health care bills exceeding $2,500 in 1977, those with Medicare alone spent 53 percent of their incomes out-of-pocket on health care expenses, those with Medicare and Medicaid spent 10 percent of their incomes, and those with both Medicare and private health insurance spent 30 percent of their incomes on out-of-pocket expenses. These figures are based on those living at home; the financial burden of nursing home care for those elderly not eligible for Medicaid can pose even greater hardships.

Heavy financial burdens for those with catastrophic medical expenses can occur even for those elderly purchasing private health insurance to supplement Medicare. Few "Medi-Gap" policies pick up physician charges in excess of Medicare's allowable fees. In addition, such supplementary policies can be extremely expensive, and return few benefits in exchange for high premiums.

Access to Health Care Services

The significant deductible and coinsurance provisions in Medicare deter some of the elderly poor and near poor from obtaining care. A recent study by the National Center for Health Services Research reported that those poor and near poor elderly who have Medicare only average 4.2 physician visits per year, compared with 7 visits per year for those with both Medicare and Medicaid and 6.5 physician visits annually for those poor and near poor elderly with Medicare and private health insurance.

The study found similar differences in use of prescription drugs. Those poor and near poor elderly with both Medicare and Medicaid averaged 15 prescriptions annually, those with Medicare and private health insurance 12 drug prescriptions, and those with Medicare alone 8.7 prescriptions.

Differences in use of hospital care were also marked. Over 22 percent of the poor and near poor elderly with either Medicaid or private health insurance to supplement Medicare were hospitalized, compared with 18 percent of those with Medicare alone.

Nor can the lower utilization of the Medicare only group be attributed to better health status. Thirty-seven percent of the Medicare only poor and near poor elderly rated their as fair or poor, compared with 33 percent of those with Medicare and private health insruance and 50 percent of those with both Medicare and Medicaid.

Elderly Living Alone

The absence of adequate home and community-based long term care services is a major problem for elderly who need assistance. While the Medicaid program has expanded coverage for some poor elderly in recent years, most elderly Americans do not have public or private health insurance coverage to finance these services, and knowing where to turn to purchase such services can be extremely confusing and frustrating.

These barriers to obtaining adequate long term care services are particularly serious for those elderly living alone. In 1984, 30 percent of all elderly lived alone -- or about 8 million people -- up from 27 percent in 1970. These elderly who live alone are disproportionately very old, more likely to be poor, and much more likely to be women.

When physical or mental decline sets in limiting their ability to shop, make their own meals, dress, bathe, remember to take their medications, pay their bills, and turn off the stove, for many the only alternative is institutionalization. Single women are at much higher risk of institutionalization -- not because they are more limited than their male counterparts but because they have no one at hand to help them cope with basic household tasks. Families worry about their well-being, but may be unable to assist if they are located far away. And some elderly have no surviving children.

Recent changes in Medicare that encourage hospitals to discharge patients early can be difficult for elderly who live alone. Walking a flight of stairs or preparing a meal for an elderly person living alone following surgery can be a painful struggle. A far more humane solution to their needs must be developed than either neglect at home or insitutionalization in a strange place.

Economic Resources of the Aged

It has become fashionable to emphasize the improved well-being of the aged and to argue that they need no special assistance. Poverty rates of the aged have declined in recent years, and now fall below those of younger age groups. This progress is indeed remarkable and reflects both the importance of social security benefits in lifting the elderly out of poverty and the economic impact on younger families of periods of high unemployment. Further, the aged receive special tax breaks that are not available to younger families. As a result, the after tax income per household member was $7,845 for aged households and $6,923 for all households in 1982 -- or approximately $900 higher for the aged.

This analysis is misleading for several reasons, however. First the elderly have much higher out-of-pocket medical expenses than do the non-aged. In 1984 the elderly spent $1,060 on their own medical expenses contrasted with an estimated $310 for the nonelderly. Thus, the difference in medical expenses alone virtually eliminates the difference in net after tax income.

In addition expressing incomes on a per capita basis assumes that an elderly woman living alone has the same need for income as each child in a family of four. Since elderly households tend to be smaller, family incomes tend to be much lower than for younger families. The most appropriate way to compare incomes is with adjustment for family size -- as the official poverty figures do. Examination of the poverty rates indicate that while the poverty rate for the aged in 1984 had fallen slightly below that of the nonaged, many more elderly were clustered in the income range just above the poverty rate. Among the elderly 68 percent had incomes below twice the poverty level, compared with 37 percent of the nonaged.

But the issue is not the economic resources of the aged as a group versus those of the young. Within both the aged population and the younger population, important subgroups face major problems. In the case of the aged, the poor and near-poor aged without Medicaid coverage face major financial burdens for acute health care services. For the frail elderly and those elderly who live alone, the absence of financing for long term care services in the home or community and the absence of any system for mobilizing existing resources to meet the individual needs of the elderly are major hurdles to maintaining an independent existence. And for those chronically ill individuals requiring multiple hospitalizations or institutionalization in a nursing home the absence of adequate insurance coverage can inflict major financial burdens.

Policy Directions

The Congress could take a number of steps to deal with these inadequacies in current health and long-term care benefits for elderly people. These include:

- Expansion of Medicare acute care benefits to include, for example, prescription drugs and catastrophic expenses.

- Improved protection for the near-poor elderly, such as expanding the eligibility of near-poor elderly for buy-in to Medicare through the Medicaid program.

- Addition of long-term care coverage as an optional Medicare benefit financed by an income-related premium.
- Expansion of long-term care services to include a broader range of community-based services and a central focal point in communities for information and referral to long-term care providers.

In the debate over long-term care it should not be forgotten that Medicare, Medicaid, and other public programs are essential to assuring that many of our nation's most vulnerable citizens can live out their lives with dignity, freed of the worry of financial ruin that major illness can bring. Current fiscal problems should not cause us to lose sight of the major steps that need to be taken to improve, rather than dismantle, these programs. Thank you.

Mr. Wyden. Thank you. Thank you both for very excellent statements. I knew of your fine work back in the days when I was codirector of the Gray Panthers in Oregon. I very much appreciate the chance to have you both here today.

Before I turn to some questions, our good friend and a very strong advocate for older people, Congressman Bilirakis from Florida is here. If you would like to make any opening statement before we turn to questions, you are certainly welcome to do so.

Mr. Bilirakis. No; I will waive the opening statement. Thank you, Mr. Chairman.

Mr. Wyden. I thank the gentleman. Let me start with you, Dr. Rowe, if I may. I was very interested in your point earlier about how you feel that older people generally wait too long to secure health care.

One thing that we are continually told by this administration is that, if you just heap on more costs, more deductibles and more copayments and things of this nature, somehow that is going to change behavior out in the marketplace. People—I guess the ones utilizing the system too much—will change their behavior and hold their costs down.

What you said certainly indicates to me that older people are not engaging in excessive utilization of the system, and in fact quite the opposite—wait too long. Is that right? Do you believe that kind of theory, that we ought to heap on more costs. Is that sensible in light of the utilization you talk about?

Dr. ROWE. I think that the prevailing feeling, which is clearly a myth, is that elderly overutilize relative to their needs, and we have a picture of the elderly patient as the hypochondriac, the complaining patient, the demanding patient who has nothing else to do but go to the doctor. That is not the case.

Studies in several countries with different health care systems, including Britain and Sweden, with national health systems where there is really no financial impediment for a patient to go to a physician, such as we have in this country, as Dr. Davis outlined, have shown repeatedly that older people just don't go to the doctor with major symptoms until they progress until they are disabling, and it appears that the basis of this is agism.

They have bought into the same agism that pervades our youth-oriented culture, and if you say to them, "Why didn't you come to see the doctor? You can't hear too well, and we can help that, and you can't see well, and you have trouble walking." They often will say, "Well, I am 83 and that is what I expected. Isn't that what you should be like when you are 83?" So they prevent themselves from coming soon enough to obtain less expensive, more efficient treatment, and they wind up on our doorstep in a crisis in the emergency room in the middle of the night needing more expensive care.

What to do about this? Other than try to change Members of Congress' mind other than those present, who obviously are aware of this problem, we need some sort of a surveillance program, some sort of a casefinding program well targeted, not too expensive, not shot-gunning it, but to identify those people with treatable, underlying diseases who are not seeking help.

Mr. WYDEN. And you think that this kind of surveillance system is the key to having older people come in earlier?

Dr. ROWE. That's right. I think you could target it, because we know what the subgroups are. We know what the risk factors are, and you could target it in such a way that you might be able to identify people with illness before it became so progressive, that is, expensive.

Mr. WYDEN. Do you think earlier attention would also reduce costs in addition to improving health?

Dr. ROWE. Whether the entire system would reduce cost would depend on how well targeted it was, it is likely not to increase costs. Budget neutral—isn't that the term?

Mr. WYDEN. That is the buzz word.

Some persons have argued that there really isn't a need to expand long-term care services. They essentially argue that if you just improve the coordination of the existing services, things will get better. Would you comment on this view in light of your knowledge of the availability of services under the existing programs?

Dr. ROWE. I don't know where those people have been, but they haven't been taking care of the elderly patient. We are already far short of the number of long-term care beds that we need, and dramatic increases in the numbers of elderly are just going to swamp us.

People will be banging on the doors of this building because they can't get their parents into nursing homes, and we have to build more nursing home beds and build them quickly. The real problem is not only increasing numbers of elderly, but the shift toward older and older ones who are much bigger utilizers. And I think it is just not realistic, to think that we have adequate long-term care services.

Mr. WYDEN. Supposing, just for a second, in an unreal world we could set aside the financing issue, Dr. Rowe. What do you think would be the best way to organize the delivery of long-term care services? Could you just sketch it out for us apart from any financing?

Dr. ROWE. We have models in many Western countries that are ahead of us demographically, that have shown us some ways in which it might be useful. What we clearly need is a continuum of services, so that the people who don't require long-term care services aren't in nursing homes just because there is no place they can get what they do need.

Any day you and I can walk down to a nursing home and discharge many of the patients, because they don't need nursing home care, but the fact is there is no place to send them to get the care they need. And we need some vertically integrated system of care so that people can go from one to another aspect of it without lots of gates and constraints.

People don't realize how frequently elderly patients bounce back and forth from the acute care hospital to the nursing home. It is one of the beauties of the VA that they are a verticae integrated system, and they can do that within the system without a lot of paperwork in different agencies.

In a broad brush, that is what we need. That is not what we have. In the continuum of need we have got an outpost at one end and an outpost at the other end, and not much in between.

Mr. WYDEN. I think your point about bouncing people back and forth is a very, very important one. We have seen that with the 3-day rule, for example. You have to go to a hospital for 3 days in order to be eligible for a skilled nursing facility. It is just absurd. I have been trying since I have been in Congress to try to change that. Your point is a very good one.

Just another couple of questions for you, Dr. Rowe.

The committee is very interested in a point that you have made. We keep hearing reports that under the Medicare DRG system some older people seem to be discharged quicker and sicker. We hear that many of them still need acute care and therefore have to go to nursing homes.

It seems to me there is a real danger of not only doing something deleterious to the health of older people, but also cancelling out any cost savings. Is that right?

Dr. ROWE. That is right. Well, let's take the example of a surgical patient.

If the surgical patient is in a long-term care facility prematurely after their gall bladder is removed or their fractured hip is repaired, it is possible that they would have a higher likelihood of complications from the surgery, which would necessitate readmission.

It is also likely that they might need physiotherapy or rehab for a longer period of time, because it was less intensive. They may be less likely to get their medicines correctly because they are on a lot of post op medications and they are in a less sophisticated setting with less capabilities for acute care.

It is obvious that you don't want your mother going from the recovery room to the nursing home, and the hospital is the one that pulls the plug. The hospital says out. It doesn't negotiate with the patient as to whether it is time to go out. It doesn't negotiate with the nursing home as to whether they are willing to take the patient. They just pull the plug.

Mr. **Bilirakis**. Would the gentleman yield a moment?

Mr. **Wyden**. I would be happy to yield to my friend.

Mr. **Bilirakis**. Is this area you have just explained to us more prevalant now under the DRG system?

Dr. **Rowe**. Yes; under the DRG system, the hospital is paid a flat rate for that patient, that age, with that diagnosis irrespective of length of stay, but the hospital's costs are related to the length of stay.

Before, that was not the case, because they were being paid on a daily basis.

Mr. **Bilirakis**. But the statistics do support the fact that many of these people are being shuffled around, being discharged?

Dr. **Rowe**. The statistics clearly show that length of stay is shorter, and if length of stay is shorter, then patients going to nursing homes—which is the population we are talking about today—are going sooner, and in many cases it is too soon, in my clinical estimation.

Mr. **Bilirakis**. Thank you, Mr. Chairman.

Mr. **Wyden**. Just a couple of other questions, doctor.

I guess the obvious one after your last comment—what kind of suggestions would you have to change PPS, change the prospective payment system, so that we don't have this problem of the premature discharges, of our older people being bounced around?

Dr. **Rowe**. Well, there are several options that come to mind, and we don't have the time to get into them all.

One option is to fund the hospital. You could say after X number of days with disfunctional frail elderly, "We will give you some payment" per capita—"for each day, because we realize you should keep them longer."

You know that is reasonable. The second thing is to make a deal with the nursing home and say, "We will give you X dollars extra to take care of these patients, so you can enhance up your capability."

My preference would be to go with the demonstrated capability of the hospitals because they are having problems with census, and they are more likely to want to keep the patient if they can get some reimbursement than to go to the lesser capability in the nursing home where you have to develop capability, also they don't generally have a census problem, and so they may not want to do it.

Mr. **Wyden**. Thoughtful suggestions and ones I know we are going to explore.

One last question for you, Dr. Rowe. I am saving you for the next round, Dr. Davis.

Dr. Rowe, as you know, Medicare coverage for the victims of Alzheimer's is essentially nonexistent. This is because Medicare doesn't offer the kinds of services needed by Alzheimer's patients and their families.

I think what we would be interested in knowing two things from you: what types of services are really required here; and is Medicare, in your view, the appropriate mechanism to provide them?

Dr. **Rowe**. Very quickly, three aspects of this. These are excellent questions.

Mr. **Wyden**. We have a very talented staff.

Dr. **Rowe**. Medicare is as good a mechanism as any. It is always hard to start a new mechanism up, easier to use an existing one.

Two things about Alzheimer's: one is that there is no such thing as the usual Alzheimer's patient's need. If you have seen one Alzheimer's patient, you have seen one Alzheimer's patient. They progress from being nearly normal to being terribly disabled over a period of years. They need anything from chore services to surveillances to nursing home care. So you need some system that can provide any kind of service, depending on the stage of the patient. We can't target certain services.

The second is that it is a major mistake if people think if you have Alzheimer's, you don't have anything else. Well, Alzheimer's is not protective against heart disease or diabetes or infections or broken hips.

And who gets Alzheimer's disease? Not 26-year-old flight attendants. Eighty-year-old women get Alzheimer's disease, and they have other problems. So that, if you are going to target something for the Alzheimer's patient, you have to realize that what you have is a sick old patient who has multiple problems, and the demands of the health care needs are often dictated more by the other coincident problems than they are by the Alzheimer's disease.

Mr. **Wyden**. The gentleman from Florida.

Mr. **Bilirakis**. But we can't, of course, overlook the needs of the Alzheimer's patient as far as Alzheimer's itself is concerned—long term care and more often than not, really long term care.

Dr. **Rowe**. That is correct.

Mr. **Bilirakis**. It really deteriorates and debilitates the family and certainly all of the family resources, so we cannot overlook it, can we?

Dr. **Rowe**. That is right. I think Alzheimer's is a single disease, but when you get in trouble we obviously have inadequate resources to deal with it, and we need special units and special funding programs, and I am delighted with Mr. Wyden's suggestions regarding that.

The problem is you don't design an Alzheimer's unit for Alzheimer's patients who have no other illness. When you get them in there, you find out that they are all 75 or 80 years old.

Mr. **Bilirakis**. What you are saying is you may design an Alzheimer's unit, but you have got to be aware of the fact that there are going to be medical problems in addition to Alzheimer's.

Dr. **Rowe**. Right. But if they are the major single diagnostic group in terms of expenditure, and they need special attention, I believe it is not inappropriate to have special legislation or special programs targeting that group.

Mr. **Bilirakis**. And sir, I certainly don't mean to disagree with your example of the 26-year-old airline attendant, but I think you and I both know that there are instances of young people acquiring Alzheimer's as well.

Dr. **Rowe**. Yes.

Mr. **Bilirakis**. My office received a letter not too long ago from a lady whose son in his mid-20's——

Dr. **Rowe**. That is right.

Mr. **Bilirakis** [continuing]. Has Alzheimer's.

Dr. **Rowe**. Often in families in which the disease runs——

Mr. **Bilirakis**. Doctor Rowe, staying with you for a moment again, how did you generate your great interest in the aging? I mean, you could have gone into so many specialties and certainly could be out making probably a lot more money in the outside world, etc.

Dr. **Rowe**. Well, I started with a major interest in the biology of aging. I was trained as a scientist as well as a physician and did laboratory work in aging and kidney disease and when I left the National Institute of Health and returned to Harvard to be the chief resident in medicine, I looked around the ward, and all of a sudden it was filled with old patients.

It must have been that way before. I just hadn't noticed it. And I thought to myself that the world probably needed a geriatrician more than it needed a specialist in kidney disease.

Mr. **Bilirakis**. I certainly commend you for that, because God knows you are correct, and it is probably the toughest type of practice, I would imagine, or certianly one of the toughest types.

Dr. **Rowe**. It is one of the more rewarding types, but one of the hardest parts is the biases of organized medicine and one's colleagues against the field of geriatrics, but I think we are starting to get somewhere with regard to that.

Mr. **Bilirakis**. Mr. Wyden, in one of his questions, mentioned discarding for the moment the real world, forgetting about finances et cetera. Unfortunately, of course, we have the real world, and the real world includes finances. And within that real world, we have got to come up with solutions, and I think that all of us in this room would probably admit that the solutions have got to be varied.

They have to include government to a certain extent but not depend on government 100 percent.

You have mentioned surveillance programs which, I guess, is part of a wellness concept which is just great. I have heard wellness over and over again, but your surveillance program is something that I haven't heard about.

There is a great interest, by the way, in long term care and particularly Alzheimer's on this committee. We have held other hearings on it and we are going to hold hearings on it in the future.

I have introduced a couple of bills on the subject, as I know many of my colleagues have. Our Chairman's interest is great in this area.

What really are our alternatives? Certainly the alternatives should not be either support it 100 percent by government or no care.

Dr. **Rowe**. Right.

Mr. **Bilirakis**. For the person who needs it, I should think the alternatives must be somewhere in between. You would agree there?

Dr. **Rowe**. I think, if I can answer that——

Mr. **Bilirakis**. Certainly, go ahead.

Dr. **Rowe**. I think we are all aware, as Dr. Davis has reminded us, that we are not 100 percent supported by government now. We are about two-thirds supported by government in terms of the health care needs of the elderly.

I think that what will happen—and my colleague, Dr. Davis, is an internationally recognized expert in this area, and I am not—what will happen is that a long-term care insurance vehicle will be developed which will be satisfactory to the market place and may provide people with an opportunity to transfer the equity in their homes or other aspects into long term care assistance.

That is going to be helpful to many but is going to require close coordination with federal programs so that major gaps don't persist.

I hope the insurance industry in this country will respond because there is a market, and they will respond in a competitive way, fortunately, so that hopefully, it will fit.

It will take care of some of these people Dr. Davis is talking about. That $10,000-a-year woman might get help, but people below that level aren't really going to be in a market for that. But I think it would be appropriate to get Dr. Davis' view on this.

Mr. **Bilirakis**. They won't be in the market because they won't be able to afford to pay the premiums.

Dr. **Rowe**. Pay the premiums, yes.

Mr. **Wyden**. Dr. Davis, would you like to add to that?

Mr. **Bilirakis**. Please do.

Mr. **Wyden**. I note this is an area you have done great work in.

Ms. **Davis**. I agree we have to start getting vehicles whether they are private or public, particularly for this expensive nursing home long-term care problem.

I am a little bit skeptical whether the private insurance industry is going to be eager to take on high risk people.

Mr. **Bilirakis**. We can help them out.

Ms. **Davis**. One thing we can consider, certainly, to encourage that to take place—and it may take place in some instances—is to offer an alternative through Medicare of voluntary long-term care insurance.

If that were offered at a premium, maybe even a premium that varied with income, then you would put some limit on private health insurance premiums.

People would have a choice. I think that way you would make sure you didn't get excessively high premiums on the private side, which I think has always been a problem that we have seen with the "Medigap" policies that have supplemented acute care benefits with Medicare.

Dr. **Rowe**. I would certainly agree with that. I didn't mean to exclude tht commonly discussed option. It would be critical to the success. Otherwise, there would be a major gap of people not covered.

Mr. Bilirakis. HMO's—I suppose we should not be excluding them from the content of this hearing, should we, Mr. Chairman? I am not sure that they are quite appropriate, but they may be.

Mr. Wyden. By no means, and I think our witnesses later are going to talk, for example, about the new concept of a social health maintenance organization.

In my congressional district in Portland, OR, we have really been one of the leaders in this area. So, I think we are going to talk about a whole host of new approaches including health maintenance organizations and the variations, the social health maintenance organizations, a new approach to offering older people services in their homes. They ought to be part of the vanguard.

Mr. Bilirakis. In that connection, regardless of whether the current HMO concept is at all adequate to cover long term care—are the current concepts, as we know them, doing the job?

Dr. Rowe. Are HMO's?

Mr. Bilirakis. Yes; limiting it not to the long-term care but limiting it to the area——

Dr. Rowe. No. The experience is there is a number now that are very rapidly increasing the numbers of elderly clients. The experience in the medical literature is that, depending uon the structure of the HMO, et cetera it appears they can provide good health care to the elderly at somewhat less cost, perhaps 10 percent less than alternative systems.

Mr. Bilirakis. That is the point I want to get to, but I wanted to hear from Dr. Davis at this point.

Ms. Davis. I think there has been a promising performance, but we are talking about two percent of the elderly that belong to HMOs. Many have had a physician for a long period of time, a certain level of care, and I do not think you will find this alternative encompassing the majority of elderly people, but I think it is important that it be there as an option.

Mr. Bilirakis. Just a few week ago, I sent out a questionnaire to my constituents. I represent a portion of Florida, the Gulf Coast, that contains a lot of elderly. If we start at age 55 on up, probably a good 50 percent of my constituents are on the HMOs. In the questionnaire, we ask for their comments in terms of whether or not HMO's are functioning adequately to satisfy them. The result comes out 50–50, if you will. If the HMO's within the current concept are doing the job and within the reimbursement being received from Medicare, does that tell us something? Does that tell us then that the dollars that are provided by the federal government for Medicare are really adequate and we do not have to bill the patient for any more? I guess I did not phrase that as well as I would like to, but the jury is still out as far as I am concerned on HMOs. I have no negative feelings toward them, but I get a lot of constituents asking me questions, and I should not be in a position of saying yes or no. You are right, a lot prefer their own doctors. Many travel from Florida, for instance, and spend part of their summers up north and they may not have any coverage up there and that is their great concern.

What I am wondering about is the concept more than anything else I suppose. Might that be one of our alternatives? You indicated you do not think it is going to be the alternative, because many of the elderly are not going to sign up for it. Might that not be an alternative in addition to surveillance and wellness?

Ms. **Davis**. I think it is an important alternative. There is considerable evidence that they can be less expensive than the fee-for-service traditional health system.

Mr. **Bilirakis**. Why?

Ms. **Davis**. They have less of an incentive to put them in hospitals. They have lower hospitalization rates. They are more likely to provide care on an ambulatory basis.

Mr. **Bilirakis**. Is that care adequate as far as the patient is concerned?

Ms. **Davis**. It varies by the type of health maintenance organization. Some have been around a long time and have a good record with regard to quality care, so that there are examples of high quality care. That is not to say that every organization ever set up on that basis and paid on that basis could be guaranteed to provide high quality care.

Mr. **Bilirakis**. Do you have a degree of negativism in your mind as far as care is concerned? The fact that they do not have the motivation and the reward of putting them into the hospital? Do you feel there are many instances where a patient does not get the proper care?

Ms. **Davis**. We have not seen that with the health care organizations. We have seen that with the fee for services, there is too much of a tendency to put them in the hospital and too much of a tendency to get them out too fast. I think it would be a mistake to say we are going to enroll all the elderly in Tampa in an HMO and that is their only choice; but if it is there as an option and if they are not happy with the service and quality of care there, there are other alternatives.

Mr. **Bilirakis**. I have one more general question without expecting an answer from you at this time. You two have shown a great interest in this subject. Have you set up a plan where, if you had the control, let's say if you were Congress et cetera, and could make the determination for what type of medical plan should be in existence in this country to cover, let's limit it for the time being to your area, long-term care, have you sat down and actually drafted up such a plan, whether you have done it in writing or in your minds? You probably have, have you not? And it certainly is hopefully not only saying the federal government ought to handle the whole thing, or is that basically the plan, that there ought to be more dollars coming from the government?

Ms. **Davis**. I think there are important things that could be done. Medicare, Medicaid and other public programs do pick up two-thirds of the health and long-term care of the elderly, so I think it would be a mistake to think we could do it all privately or publicly. So I think we will have a combination. I think we should build on the current programs, look at their problems and make basic changes in those.

Mr. **Bilirakis**. I would like, on behalf of the committee, to invite comments from both of you. If you were able to make the determination on what should be done, particularly within the realm of what Congress can exercise, we would appreciate your submitting your comments to us. I would also appreciate a copy of whatever they might submit for the record.

Mr. **Wyden**. I think the gentleman's suggestion is first rate and we will leave the record open for Dr. Davis and Dr. Rowe to give us additional comments about their approaches in writing. We will make sure the gentleman from Florida has them.

Mr. **Bilirakis**. Thank you.

Mr. **Wyden**. Just a couple of questions I have for you, Dr. Davis. You have written over the years consistently and very well. I know, because I have used a lot of your information about the gaps in coverage for older people and their health care needs. Would you say at this point that long-term care is the great unmet need for older people in this country?

Ms. **Davis**. I think it is a very serious problem. If you look in terms of numbers, of course one is talking about a million out of 27 million elderly people who are in nursing homes. So in terms of the proportion of population I do not think we should have an image that all the elderly are frail and require nursing home care. We have a million in nursing homes and a million in the home needing assistance. In terms of the severity of the problem for those two million people, it is a financial problem because there is no way of paying for that long-term care except to destitute yourself and become eligible for Medicaid and for the person at home finding the services you need and knowing where the family can turn to get relief from the demands on the family trying to support the frail person at home. I think it is important to take some steps to improve that situation.

Mr. **Wyden**. Are there other priorities that should be placed ahead of long-term care at this point?

Ms. **Davis**. I would stress some concern with the near-poor elderly and acute care benefits. I think that one could make improvements in Medicaid by expanding the buy-in to Medicare for the near-poor elderly. I would remind the committee that that is a problem for those elderly who are not poor enough to get Medicaid but not rich enough to supplement with private health insurance. That is a problem and I think the problem of uncovered benefits and the absence of any kind of ceiling on Medicare cost sharing is also a problem for many elderly with modest incomes.

Mr. **Wyden**. What would your priorities be in the long-term care area in isolation assuming, as you said, there are several million people where you think the need is great there? In terms of your priorities what would they be in long-term care?

Ms. **Davis**. It depends on the budget you give me to work with. The first thing would be to make home and community-based services under Medicaid an optional benefit rather than to limit it through the waiver kind of provision we have now. Starting with that provision, which is already in the law, and expanding that a bit would be an important step. I think a second modest step could be some direct grants to provide what are called, in other countries, home health services so they are not health services that require an advanced health professional to provide but general home health sevices, personal care services, so direct grants to local organizations, whether those are municipal or nonprofit organizations, that would be available as a focal point to provide those kinds of services in communities. Setting up an information and referral network, just knowing a telephone number in a community that you can call and be told, is there a day hospital program for a family member with Alzheimer's in this community, am I eligible, how do I get to it; so some kind of information referral network.

Those are relatively modest things that I think could be done that would make an improvement. I think the big thing that needs to be done is providing some kind of insurance for nursing home care, and I think there are some proposals to do that such as offering through Medicare a voluntary long-term care insurance plan which would be self-financed, in large part, through a premium.

Mr. **Wyden**. Tell me how that would work. Do you think those premiums could do it alone? In other words, there would not have to be new moneys from the trust fund if you were to add a long-term care insurance concept?

Ms. **Davis**. It is possible. We do not have a lot of experience so it is hard to be too certain. I am envisioning not something that would be totally public but require some public contribution. You might require, for example, for nursing home care that they pay 10 percent of the costs up to some ceiling, $3,000 or $4,000, because if they were at home instead of in a nursing home they would be paying for food and certain expenses. So I think it is reasonable to expect under any benefit package that there might be some cost sharing for these kinds of services.

But if there is a ceiling, you would find families thinking this is something doable. When they are faced with a $20,000 to $30,000 bill every year for 3 to 5 years, no family thinks they can absorb that kind of cost. So what happens is they become destitute, spend down and then it is totally public coverage. If you have an insurance plan where they contribute a premium, that they pay some of the cost, it would be financially doable for the individual and the family. You would have to build in some protection. For example, if you did it through a Medicare plan, you would want them to be enrolled for at least a period of time before they are eligible for benefits. You might have them enroll at age 60, not get benefits until 70, most likely until 85 and are frail enough to require the care. So you get premiums to finance the system well in advance of the time.

Some estimate if we were to set a premium at roughly 4 percent of income and you got a representative group of elderly people, you did not just get the very sickest people, you could have a self-financing type plan.

Mr. **Bilirakis**. Excuse me, Mr. Chairman.

Will your thoughts be part of the submittal to the record?

Ms. **Davis**. Yes, sir.

Mr. **Bilirakis**. Fine.

Mr. **Wyden**. A couple of other questions.

What do you think is going to happen in the years ahead with respect to the figures on income for older people? We have many experts saying that the income for many is going to soar and there are others who are more doubtful. I gather that you are one who is somewhat skeptical of whether older people are going to have sufficiently large incomes to be able to afford private packages and things of that nature. I think we would be interested for the record in your thoughts on the future of elders' income.

Ms. **Davis**. I think there are some elderly who will be better off in the future. The standard of living for everyone goes up, sometimes imperceptibly, but we expect over time it will continue to rise. In addition, the elderly by 2000, 2030 will be a much more educated group. The levels of education are higher in the upcoming cohorts. In addition, more women have been in the workplace, so you have more two-earner families and a base from it. So there are some things that indicate that the income will go up.

On the other hand, we know that the health care costs will be a lot higher in the future than they are today, so these kinds of gaps, if we do not do something about them, are going to inflict even greater financial burdens on elderly people over time, and the problem is not an average problem. It is a subgroup problem. You have a distribution now. You have gotten some of the elderly out of poverty, but now they are clustered in the near-poor income range, and in the year 2000 even if you have some that are well to do, you will still have the problem of a number at the lower ends.

I think some groups will be able to pay more and to build in a plan such as one that is financed through an income-related premium would let them contribute as they are able to.

Mr. **Wyden**. One thing I feel about private insurance is that, to some extent, with private long-term care insurance it is demand out there looking for a supply. I think if we can just boost it along with legislation like mine to share information and guidelines about what policies ought to look like for both the industry and consumers not mandatory guidelines or some kind of coercive Government program, I think we can come up with an approach that is going to be able to be attractive to a significant portion of the market. One of the reasons I like it is that that will free up the limited Government resources for those who can afford it. I wonder if you might want to comment on that as an appraisal.

Ms. **Davis**. I think certainly trying to encourage that, set standards for that would be a good step, but I think what we have seen with some of the private plans is that they try to selectively market to the relatively healthy, so retired schoolteachers, college professors are a great group to try to get into a long-term care insurance plan, but you do not want to move into communities that have serious poverty or a high incidence of chronic conditions. So I think what you have to worry about is whether they will try to get the 80 percent of the elderly who are never going to wind up in nursing homes and market to them. I do not think that is going to be a complete solution and am skeptical that it will be a major solution.

Mr. **Wyden**. I share your concern about what is called adverse selection, in effect, those who are healthiest and those who are most well today. It just seems to me that any time, when you have limited resources, if you have a private sector remedy for some who can afford it, that is all to the good. Then we can go forward and do what needs to be done, which you have correctly identified, which is to have a little more available for low-income people.

I look forward to working with you on these kinds of things in the days ahead. I think the concerns are very valid. It seems to me that when we have so few resources and that $2 trillion debt staring at us, we are ahead any time we can come up with some private sector approach that can meet some needs. I said in my opening statement I do not think it is going to meet all of them. There are a lot of low-income older people who cannot afford it. I think we ought to go forward and do it. We find the job is easier with the expertise of you and Dr. Rowe. You talked about the older people who live alone. We know that they are very vulnerable. We would be interested in knowing whether you think there are some services that we ought to tailor just to them and whether it is going to take a special kind of approach to deal with that group of often vulnerable people.

Ms. **Davis**. I think that there are some things that we need to worry about with the elderly living alone. Dr. Rowe mentioned the prospective payment system and its incentive for early discharge. I think we need to worry about this a lot with regard to the patient with no one at home to help them. So if they have to walk up steps, fix a meal, it is tougher for them. So particular provisions, whether it is a continuing payment rate to the hospital to keep those elderly that live alone a little bit longer in the hospital or some foster care situations so that there is a place they can go for a few weeks while they convalesce or whether it is a nursing home or different type of care setting, but I think that the elderly patient who lives alone cannot cope with an early discharge from a hospital the way a patient can who has a spouse or other members at home to help with the tasks. So I think the hospital discharge is something we need to worry about.

In addition, I think these people need more intensive both home health services and also the home help service. They are going to need more frequent visits during the week of some outside personnel coming in to provide these types of assistance. So I think particularly setting up some type of a direct grant program for these home help services would be of particular benefit to these elderly individuals who live alone.

Mr. **Bilirakis**. I ask, from the standpoint of the long-term care patient, what, if anything, should we be trying to do as far as malpractice is concerned? You mentioned the increase, continued increase in medical costs et cetera. That certainly is part of it.

Dr. **Rowe**. I mean I do not know if you are referring to the possibility that there is too much malpractice or whether the issue that malpractice premiums are so high for physicians practicing geriatrics, this is not a high malpractice area like obstetrics or orthopedics. I want to address the general issue.

I think that one of the things that we could do to improve the health care of the elderly in this country, and that is what we are talking about here, is it might not be a bad idea if we had some more geriatricians. In your district in the west coast of Florida and in Mr. Wyden's district there are cities with geriatricians. The growth of geriatrics as a specialty in medicine has occurred at the same time that the Federal Government has decided not to support training programs for medical specialists. So we are caught in the middle. If you want to improve the health care of elderly in long-term care facilities, improve the training of doctors in the health care of the elderly.

Mr. **Bilirakis**. You are getting away from the original question. Going to what you have just told us, should we, in a sense, be encouraging the medical schools, as far as their selection process is concerned, to see that more people go into that? Right now, as far as I am concerned, and I have personal experience, it is done on a cold type of a basis. If you have a certain undergraduate score, you get into medical school and your particular interest is forgotten later on.

Dr. **Rowe**. I agree. The criteria to get into medical school is stringent. Years of experience have shown the difficulty in selecting medical students based on whether you think they are going to go into practice or research or whatever. We have a research-intensive medical school and most of our graduates wind up in practice. You cannot really judge college students as to that ultimate career before they have the experience of medical school. You can encourage and support medical schools in teaching geriatrics to the students. When I graduated from medical school, in 1970, there was no curriculum in geriatrics. As of last year approximately 50 percent of medical schools had geriatrics in the curriculum, so we need support for medical schools to include geriatrics and to train people to be geriatricians. There are very few resources available to support the training of doctors who want to take care of the patients in nursing homes. That is the problem and it is a major problem.

Mr. **Bilirakis**. Thank you. I certainly agree with you there, although I sometimes think maybe since federal dollars go a long way towards medical education—and I am a free enterpriser—but I wonder if we should take a little bit of a lead insofar as being sure that the certain specialties where we do have a shortage are, in fact, filled in some way or another?

But on malpractice, my concern is that, from the patient standpoint, it would seem that there should not be any limitations in terms of malpractice amounts, the recovery amounts and things of that nature. From the patient standpoint, it would seem, and yet from the patient standpoint also medical costs keep going up and that is a very salient reason why, not the only reason, but a salient reason why they are going up. So what should we be doing, if anything, in that regard from the patient standpoint?

Very quickly. I know we are taking a long time here.

Dr. **Rowe**. What I would like to do, given the time, is provide you with some detailed response to that.

Mr. **Bilirakis**. That would be fine.

Dr. Davis, if we could get some sort of response from you in that regard too, again from the patient standpoint, I would appreciate it. My appreciation to both of you for taking time to come here this morning.

Mr. **Wyden**. Unless either of you have further comments, we thank you for giving us all this time this morning. As usual, you give us much to follow up on and to work with, and we thank you both.

[Testimony resumes on p. 66.]

[The following letter and attachments were submitted for the record:]

THE JOHNS HOPKINS UNIVERSITY
School of Hygiene and Public Health
Department of Health Policy and Management

Karen Davis, Chairman
301-955-3625

October 31, 1985

The Honorable Henry A. Waxman, Chairman
Subcommittee on Health and the Environment
Committee on Energy and Commerce
U.S. House of Representatives
2415 Rayburn House Office Building
Washington, D.C. 20515

Dear Mr. Waxman:

I am writing to thank you for the opportunity of testifying before the Subcommittee on Health and the Environment on the health and long-term care needs of the elderly on October 18, 1985.

In response to Representative Bilirakis' request for further information regarding a plan for long-term care, I am submitting for the record the final chapter from my book entitled Medicare Policy: New Directions for Health and Long-Term Care. This book will be released this November by The Johns Hopkins University Press.

This chapter presents an overview of my views on the need for an integrated approach to reforming the financing of acute and long-term care for the elderly. This approach is analyzed in terms of impact on beneficiaries, financing and administrative feasibility. I would be happy to work further with the Subcommittee to develop an effective initiative in this important area.

In addition, Representative Bilirakis requested information on the malpractice area. I am, therefore, submitting for the record a memorandum from Dr. Laura Morlock on malpractice issues. Dr. Morlock, an associate professor in the Department of Health Policy at The Johns Hopkins School of Hygiene and Public Health, is conducting a detailed analysis of the malpractice claims involving physicians and hospitals in Maryland.

Again, thank you. If I can be of any further assistance to the Subcommittee, please let me know.

Sincerely,

Karen Davis

Karen Davis

MEMORANDUM

TO: The Honorable Henry A. Waxman, Chairman
Subcommittee on Health and the Environment
Committee on Energy and Commerce
U.S. House of Representatives
2415 Rayburn House Office Building
Washington, D.C. 20515

FROM: Laura L. Morlock, Ph.D.
Associate Professor
Department of Health Policy and Management
School of Hygiene and Public Health
The Johns Hopkins University
624 N. Broadway
Baltimore, Maryland 21205

DATE: November 6, 1985

RE: Impact of Malpractice Issues on Health Care Costs

The following memorandum summarizes available evidence regarding the current impact of malpractice issues on health care costs. It is submitted for the record in response to a request from Representative Bilirakis during the October 18, 1985 hearing held by the Subcommittee on Health and the Environment on the health and long term care needs of the elderly. Included in the discussion are the following: recent trends regarding frequency of malpractice claims and size of settlements and awards to claimants; recent trends with respect to the cost of liability insurance premiums; estimated costs of "defensive medicine", and; estimated costs to patients and the health care system of provider negligence.

Frequency of Malpractice Claims: Recent Trends

Professional liability claims against health care providers began to increase rapidly during the first half of the 1970s, declined in frequency during 1975-78, and then began to increase significantly after 1979. Most estimates of claims incidence show at least a doubling in claims frequency after 1978. The National Association of Insurance Commissioners found that the average incidence was 3.3 claims per 100 physicians prior to 1978, and 8.0 claims per 100 physicians during the late 1970s and early 1980s.[1] According to statistics compiled by the American Medical Association which are based on their national surveys of physicians, in the years prior to 1980 there were an average of 3.3 claims for every 100 physicians; between 1980 and 1984 the number of filed claims per 100 physicians increased to 8.4.[2] Significant increases also have been experienced in claims against hospitals: The St. Paul Companies, for example, have reported that hospital claims rose from 1.75 per 100 beds in 1979 to 3.0 per 100 beds in 1983.[3]

The frequency of malpractice claims has been shown to vary substantially, however, by geographic area, by specialty and by other provider characteristics. Adams and Zuckerman analyzed data from the AMA's 1982 Socioeconomic Monitoring System survey of 3817 physicians.[4] These data indicate that, on average, physicians incurred twice as many claims per year during 1976-1981 as they did during their careers prior to that period. The annual frequency of claims was found to be greater among surgeons, obstetricians and gynecologists (OBGs), physicians in group practice, and physicians in states which apply the legal doctrine of informed consent. Analysis results also suggest that the number of years since medical residency is positively related to physicians' claims incidence during the first 27 years of practice, and that OBGs and medical specialtists who report spending more time with their patients per office visit, on average, incur fewer claims.

Data collected through interviews with 1241 physicians by the AMA's Socioeconomic Monitoring System during 1983 examined changes before and after 1978 in the incidence of claims.[5] The increase in the annual rate of claims between the two time periods was statistically significant for general and family practitioners, surgeons, physicians in the northeast and north central regions, male physicians and those practicing in urban areas.

The frequency of malpractice claims against obstetricians and gynecologists has been viewed as particularly problematic. The American College of Obstetrics and Gynecology (ACOG) has reported that the frequency of lawsuits against OBGs tripled between 1979 and 1984. Sixty percent of OBGs have been sued at least once; 20% have had three or more claims filed against them, while almost half of New York State OBGs have been sued at least three times.[6]

Recent Trends in Size of Awards/Settlements

The average size of malpractice awards and settlements has experienced first a steady increase and then a dramatic upswing during the entire 1975-1984 time period. The St. Paul Companies have experienced growth in average loss per physician claim (a figure that includes allocated loss expense, including defense and administrative costs) from approximately $9000 in 1974 to $23,000 in 1984.[7] During this same time period St. Paul's average loss for claims against hospitals rose from approximately $5800 to $12,300. Data from physician-owned insurers indicate an increase in average paid loss per claim from $20,396 in 1979 to $72,243 in 1983.[8]

Juries (and panels under pretrial screening and arbitration mechanisms) resolve only a small percentage of malpractice claims, but jury and panel awards are known to influence the level of out-of-court settlements, and are believed to provide incentives for patients and attorneys to pursue claims. According to Jury Verdict Research, one reporting service, the midpoint (median) of a typical verdict against a physician was $48,500 in 1975, and the average was $94,947. For 1983-84, the reported midpoint verdict was $200,637, and the average was $338,463.[9] During the past decade very large awards have become increasingly common: Only 4 awards of $1 million or more were reported to Jury Verdict Research in 1976, compared to 45 such awards in 1981 and 70 in 1983. The St. Paul Companies, who currently have a 15% share of the national medical malpractice insurance market, report that they are now experiencing a $1 million settlement or verdict every week.[10]

The average cost per malpractice claim, like claim frequency, varies significantly by state, with a thirtyfold range between the most and least litigious states.[11] Size of awards and settlements also vary dramatically by specialty, with obstetrics/gynecology ranked highest due to the increasingly large payouts (often $1 million or more) in cases involving birth-injured infants.

Cost of Liability Insurance Premiums

Growth in average malpractice premium costs during 1976-1983 in general was much slower than growth in the frequency of claims, size of awards and settlements, or than increases in the Medical Care Price Index. The National Conference of State Legislatures reports that between 1976 and 1983, average physician premium expenses grew only 51% (from $4700 to $7100)--well below the nearly 100% increase in the Medical Care Price Index for the same period.[12] According to AMA-compiled statistics, average malpractice premium expenses equaled 4.4% of gross income for physicians in 1976, compared to 3.7% of gross income in 1983.

In the last two years, however, malpractice insurance premiums have increased significantly. While insurance premiums for the total medical professional liability industry increased 30.8% between 1977 and 1983 (from $1.20 billion to $1.57 billion), malpractice insurance losses soared 144.8% (from $817 million in 1979 to approximately $2 billion in 1983). During the late 1970's and early 1980's, return on investments at high interest rates still permitted overall profit-making among companies writing malpractice insurance. By 1984, however, Best's Insurance Management Reports concluded that "medical malpractice is reaching the point of no return in terms of producing investment income from loss reserves that exceeds the underwriting loss."[13] Insurance companies have responded with substantial increases in malpractice insurance premiums. St. Paul's rates, for example, rose 15-20% per year for physicians during the early 1980's, increased on average by 25-30% in 1984 and are expected to increase by another 30% this year.

Growth in premiums has varied substantially by geographic area and by specialty: Physicians in urbanized areas; in states such as New York, California and Florida; and in "high-risk" specialties such as Obstetrics, Anesthesiology and Neurosurgery have been particularly hard hit. According to AMA data, for example, the premium for all physicians rose 434% between 1970 and 1982. The increase for general and family practitioners during this time period was 270%, however, while the increase was 528% for surgeons.[14] St. Paul's rates effective July 1, 1985 for $1 million/$3 million coverage were $1369 for a relatively low-risk General Practitioner in Arkansas, compared to $92,570 for the same level of coverage for a Miami neurosurgeon.[15] St. Paul's rates for hospitals ranged from a little over $200 per bed in South Carolina to over $1000 per bed in Florida.

Impact of Increasing Liability Premiums on Health Care Costs

It is frequently argued that escalating liability insurance premiums are increasing consumer's health care costs. The California Medical Association estimated, for example, that in 1982 malpractice insurance premiums added $5 a day to the cost of every hospital stay and $3-4 to the cost of every visit to a doctor. The New York State insurance department estimated that

15-17% of a recent Blue Cross/Blue Shield premium increase went to hospitals' insurance bills.

The direct costs of the recent increase in malpractice claims and awards are usually cited as the amounts paid by providers in insurance premiums (currently estimated at approximately $2 billion per year), the funds used to underwrite provider-owned insurance companies, the costs of risk management programs, and fees for legal counsel. In addition, it is frequently argued that the current malpractice situation contributes to health care costs through the practice of "defensive medicine"--defined as unnecessary procedures performed by health care providers in order to protect themselves against potential lawsuits. The AMA currently estimates that the "extra" diagnostic tests and procedures of defensive medicine increase expenses by approximately $15.1 billion per year.[16] This figure is an estimate based on responses to a 1983 survey of practicing physicians conducted by the AMA. Forty-one per cent of physicians responding to the survey indicated that they prescribed additional tests because of the fear of litigation; 27.2% provided additional treatment procedures; 35.9% spent extra time with patients; 56.7% kept more detailed records; 44% referred more cases to other physicians; 34.6% no longer accepted certain kinds of cases; and 31.4% said they had raised their fees to compensate for the increased costs of insurance premiums.[17]

It should be noted, however, that critics of the AMA's position, such as Patricia Danzon, argue that the malpractice system functions as a deterrent to improper and negligent treatment. She has argued in Senate testimony that certain "defensive" activities, such as increased time with patients and the referral of difficult cases "are precisely the types of increased care which the malpractice system is intended to encourage."[18] Danzon also points out that it is impossible to distinguish defensive medicine from the over-utilization that results from the economic incentives inherent in fee-for-service medicine.

Estimated Costs of Provider Negligence

Injuries resulting from provider negligence also must be considered a significant cost to the health care system. Danzon argues, for example, that the real cost of malpractice is the cost of medical injury, which she estimates at $24 billion a year. This estimate is based on a detailed study conducted by Don Harper Mills in 1974 for the California Hospital Association and the California Medical Association. Study results indicated that about one in 126 hospital admissions leads to an injury due to medical negligence. Using these data, Danzon concluded that "at most one in 10 of these injured patients filed a claim, and at most one in 25 received compensation through the tort system."[19]

It should be noted that awarding reparations for iatrogenic injuries creates no new costs but simply shifts to providers and the public costs that would otherwise be borne privately. Shifting of these costs through the current tort system, however, may in itself be expensive. Administration, claims evaluation and litigation costs (including plaintiff attorneys' contingency fees and defense attorneys' hourly fees) absorb more than half of each premium dollar.[20] Current estimates are that only 28 to 40 cents of each premium dollar ultimately goes to injured parties.[21]

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CHAPTER 6

AN INTEGRATED APPROACH TO REFORMING FINANCING OF ACUTE AND LONG-TERM CARE FOR THE ELDERLY

Reforming the financing of acute- and long-term-care services for the elderly should address several problems inherent in the current system. These include the financial burdens the elderly incur because of serious gaps in coverage and limitations on benefits, the projected deficit in the Medicare Hospital Insurance Trust Fund, the general problem of rapidly increasing expenditures for both hospital and physician services for the elderly, and the fragmented and inadequate coverage of long-term care today.

Various proposals that have been advanced address some aspect of the problems with the current system. Yet they fail both to deal comprehensively with flaws in the current approach and to take advantage of trade-offs and coordination that could be achieved by a single integrated plan. By dealing with only one aspect of the current system, they seem unlikely to address the underlying problems in a satisfactory manner.

I. A Proposal for an Integrated Approach

A more promising approach is to reform both Medicare and Medicaid to address directly, in a fiscally responsible manner, their shortcomings in meeting the health and long-term-care needs of the elderly. This involves rethinking the entire structure of the programs, including current eligibility provisions, benefits, financing sources, provider payment methods, administration, and the need for innovative features to reform the delivery of services.

The basic strategy endorsed here would be to merge the Hospital Insurance (HI) and Supplementary Medical Insurance (SMI) parts of Medicare into a single plan, develop a new voluntary long-term-care plan as part of the program, and design a separate Medicaid program for Medicare beneficiaries that would provide wrap-around protection for low-income elderly.

o Coverage. The new Medicare program would cover everyone 65 or older (not just those covered by social security) and the disabled who qualify under current eligibility provisions. The new Medicaid wrap-around coverage would be extended to all elderly poor, with a spend-down provision for the near-poor.

o Benefits. All the current Medicare benefits would continue in the new plan, but the limits on covered hospital days would be removed. Deductible and coinsurance provisions for hospital and physician services would be continued. However, a new ceiling on out-of-pocket expenses of the elderly would be incorporated, set initially at $1,500 and indexed over time with the growth in program expenditures. Expenses counting toward this maximum ceiling would include all out-of-pocket payments for hospital, physician, and other Medicare benefits, plus those for prescription drugs. Once an elderly person had paid $1,500 in a given year for these, Medicare would cover all additional expenses.

The optional long-term-care plan under Medicare would cover nursing home care (in qualified Skilled Nursing Intermediate Care Facilities), home health services (in addition to the more limited home health benefits now available in the acute-care Medicare plan), and day hospital services. These services would be subject to a 10 percent coinsurance charge, and would have a ceiling on out-of-pocket costs of $3,000 annually. Elderly Americans wanting this coverage could enroll at 60, but benefits would not be initiated until the person had been enrolled in the plan at least five years. No one could enroll after age 70. This plan would be supplemented with a direct grant program to public and non-profit community organizations to provide help at home, such as chore services and personal care services, for the functionally impaired.

The Medicaid wrap-around plan would cover the cost-sharing payment required under the acute-care part of Medicare for all elderly with incomes below the federal poverty level. A spend-down provision would assist those whose incomes after out-of-pocket expenses would be reduced to below poverty. The current Medicaid coverage of long-term care would continue as a safety net for those elderly poor unable or unwilling to obtain the voluntary long-term-care coverage under Medicare.

o Financing. HI and SMI Medicare Trust Funds would be merged. The current HI payroll tax would be retained as a source of revenue for the new fund and would continue at its current legislated rate. General revenues currently projected to support SMI would be added to the fund, and the current SMI premium would be replaced with an income-related payment. This new Medicare premium would be set at 2.5 percent of taxable income of the enrollees (compared with a current premium projected to be $203 in 1985, approximately 2.0 percent of income), and would be administered through the personal income tax system. The definition of income would be broadened, to be consistent with social security provisions for taxing the benefits of higher-income elderly.

The new premium would be capped at $1,000 annually, so that no elderly person would be required to pay a premium exceeding 50 percent of the actuarial value of Medicare. A minimum annual premium of $100 would ensure that all elderly Americans made some contribution; for those not required to pay income taxes, this minimum premium could be paid directly to Medicare. Both the minimum and maximum premium rates would be indexed over time with increases in program expenditures. Additional revenues for the Medicare Trust Fund would come from doubling the current tax on cigarettes. These funds would be earmarked for Medicare, and added to the trust fund.

Optional long-term-care coverage would be available for an income-related premium set at 4.0 percent of income for those who enroll at 60 (and increasing for those postponing enrollment), with a minimum annual premium of $200. Federal general revenues would be used to meet any long-term-care expenditures not covered by the premium (as happens now with the SMI section of Medicare). Categorical federal grant funds could establish home help service programs through public or non-profit community organizations.

The federal government would assume all the cost of Medicaid supplementation of Medicare acute-care cost-sharing. However, federal support for residual Medicaid long-term-care coverage for Medicare beneficiaries would be reduced by half the current contribution rate. For anyone receiving long-term-care through Medicaid, rather than the voluntary plan, Medicaid would assume the full cost--not just the coinsurance provisions in Medicare.

o Provider Payment. Improved benefits and expanded financing of acute and long-term care would have to be coupled with stringent cost-containment measures. The current prospective payment system for hospitals under Medicare would be retained and strengthened. A residual all-payer hospital prospective payment system covering privately insured patients as well as Medicare and Medicaid beneficiaries would be adopted for those states that do not voluntarily join in.

A prospective physician payment system would be established, and physicians would be required to accept Medicare rates for services rendered to hospital patients. A prospective payment system for nursing homes would be also be established, taking into account the level of complexity involved in the care of patients with different functional impairments. Payment on a capitation basis would be encouraged for health maintenance organizations. Demonstrations to test capitation payment for nursing home patients, covering both acute and long-term care, would be instituted as a basis for evolving a longer-term prospective payment system based on capitation.

o Delivery of Services. Appropriate care would be encouraged through the assessment of patient conditions and by making long-term-care benefits contingent upon necessity, as determined by qualified physicians. Profiles of practice patterns would be established for all benefits, and utilization review instituted for all claims falling outside accepted norms. Emphasis would be placed upon avoiding institutional care -- either in hospitals or nursing homes -- where possible. Pre-admission assessment would be required for nursing homes. Day hospital services would be covered under the voluntary long-term-care plan as an alternative to institutional care. Respite care would also be provided so that family members supporting a functionally impaired elderly person at home could have periodic breaks. Grants to public or non-profit organizations to provide home help services would enable more functionally impaired elderly to remain in their homes. These services would also be based upon need and level of dependency. Volunteers in home help agencies could earn credits to be applied toward their own voluntary long-term-care premiums.

II. Analysis of the Proposal

Several questions should be raised about any proposal to reform the Medicare program.

- What is the likely impact of the proposal on Medicare enrollees?
- How will the proposal be financed? What is its likely cost? And who will bear the burden of this cost?
- How does the proposal relate to the existing system and is it administratively feasible?

A. Impact on the Elderly

The proposed reform would remedy many of the most serious gaps in the current Medicare program. It would guarantee coverage for all the aged, regardless of income, race, or prior work history. It provides comprehensive benefits, including care for acute and chronic health conditions and assistance in coping with functional limitations. It removes the heavy financial burden that currently falls on the elderly near-poor, those with chronic conditions requiring intermittent acute care, and those who require long-term care. The financial security and peace of mind that come from a ceiling on maximum financial responsibilities for health care should go a long way toward meeting the elderly's most basic concern -- the threat of insufficient funds to receive care throughout life.

The emphasis upon alternatives to nursing home care and on adequate financial protection should nursing home care be necessary provide important new benefits to the old. Current procedures work serious hardships on those unable to care for themselves. Financial access to long-term-care services in the home or community is an important barrier presently. Only those who are impoverished can hope for some assistance from Medicaid. As a result, many middle-class elderly must enter a nursing home, exhaust their resources, and eventually qualify for Medicaid. A better alternative would to support the person or the family to ensure that care could be provided in the home.

B. Financing

The proposed system of financing would guarantee the fiscal solvency of Medicare through 1995, and through a more flexible approach, while simultaneously improving benefits. The combination of revenues from the payroll tax, general revenues, cigarette taxes, and premiums should provide a stabler source of support than the current system faces. Furthermore, if future projections prove inaccurate -- for example, if provider cost controls and incentives have more or less impact on expenditures than predicted -- premiums or the contribution from general revenues could be adjusted easily.

The deficit in the Medicare Hospital Insurance Trust Fund is projected to reach $250 billion by 1995. The proposed hospital payment limits would reduce this to $95 billion over the 1985-95 period (Ginsburg and Moon, 1984). More-recent estimates based a better performance of the economy and slower inflation in health care costs drop the projected deficit further (Medicare Trustees, 1983). Other proposed reforms of physician payments and of incentives to promote alternatives to hospital care could be expected to lower the deficit further. It is reasonable to expect that the cumulative deficit without expanded benefits or new sources of revenue would be about $50 billion over the 1985-95 period.

If fully implemented in 1985, the expanded acute-care benefit package proposed here would add $1.5 billion to the cost of Medicare. This comes from placing a $1,500 ceiling on maximum out-of-pocket expenditures (Gornick et al., 1983). Over 10 years, improved benefits could add as much as $25 billion to the cost of Medicare. Thus, the total new revenue required to both remove the current projected deficit and improve financial protection for the elderly is approximately $75 billion from 1985 to 1995.

The proposed doubling and earmarking of the cigarette tax would generate $57 billion in revenue over this period Senate Aging Committee, 1984). The proposed Medicare premium would generate an additional $25 billion in revenues. (Each 1.0 percent of income paid in premiums generates $50 billion in revenues over 1985-95; see Davis and Rowland, 1984.)

The impact of an income-related premium on different groups of the elderly hinges on the specific manner in which the premium varies with income. Table VI-1 illustrates the distributional impact of four premiums using alternative percentages of adjusted gross income. Option 1 is a fixed premium for all Medicare beneficiaries with family incomes above $10,000. No premium would be assessed for those with incomes under $5,000. Premiums for beneficiaries with incomes between $5,000 and $10,000 would be on a sliding scale. Option 2 is a premium set at a constant percent of adjusted gross income. The Premium in Option 3 is a constant percent of taxable income. Option 4 has a premium set at a constant percent of tax liability--that is, a tax surcharge.

The fixed premium would be regressive at incomes above $10,000. In other words, it would represent a higher fraction of income for the elderly with incomes between $10,000 and $15,000 than for those with incomes over $25,000. Option 2, the premium set at a fixed percentage of adjusted gross income, is by definition a proportional tax. All older Americans would pay the same fraction of income to finance Medicare. The levy on taxable income is moderately progressive. Virtually no premium would be due from someone with an income below $5,000, but the elderly with incomes above $10,000 would all pay approximately the same proportion toward the program. Option 4 -- the tax surcharge -- is the most progressive method of financing; those with incomes below $5,000 would pay virtually no premium; those between $5,000 and $10,000 would pay about 0.4 percent of income; the elderly with incomes between $10,000 and $15,000 would pay 0.9 percent; and those with incomes over $25,000 would pay almost 2.6 percent of their income.

All the options for varying the premium with income are more equitably distributed than a plan that raised similar revenues from hospital coinsurance charges. Under the premium approach, all elderly (except the low-income if so specified) would share in the financial burden. Under the hospital coinsurance approach, however, only the 20 percent of the elderly who are hospitalized would contribute toward reduction of the deficit. Those chronically ill elderly could be faced with quite burdensome contributions under hospital coinsurance. Approximately one-fifth of the elderly at all income levels are hospitalized during a year; the average days of care are somewhat higher for lower-income elderly. As shown in Table VI-2, raising a comparable amount of revenue from hospital coinsurance would place enormous financial burdens on the low-income elderly who were hospitalized. Even if Medicaid were to assume these amounts for the 3.5 million elderly it covers, serious financial burdens would be felt by people with incomes just above Medicaid eligi-

Table VI-1: Distributional Impact of Alternative Income-related Premiums,[1] 1985

Adjusted Gross Income Class	Option 1 Fixed Dollar Premium Reduced for Poor	Option 2 Premium set at constant percentage of adjusted gross income	Option 3 Premium set at constant percentage of taxable income	Option 4 Premium set at constant percentage of tax liability
	Increased Revenue as a Percent of Adjusted Gross Income			
Total	2.0%	2.0%	2.0%	2.0%
$0 - 4,999	0.0	2.0	0.1	0.0
$5,000 - 9,999	3.7	2.0	1.2	0.4
$10,000 - 14,999	4.6	2.0	2.0	0.9
$15,000 - 19,999	3.3	2.0	2.0	1.2
$20,000 - 24,999	2.5	2.0	2.1	1.4
$25,000 and over	1.0	2.0	2.1	2.6

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[1] Each option yields $5 billion revenues in 1985.

Source: Calculated from Brookings Institution 1980 personal income tax file projected to 1985. Includes effects of 1981 tax act (ERTA) and 1982 tax act (TEFRA), but not the 1983 Social Security financing plan. Estimates for disabled based on income of taxpaying units with members aged 65 and over.

bility. For example, the hospitalized elderly with incomes between the poverty level and twice the poverty level would pay 16 percent of their income. In addition, such people would be likely to incur substantial non-hospital out-of-pocket expenditures. Clearly, as a tax matter coinsurance is the most inequitable form of taxation that could be assessed on Medicare beneficaries.

Premiums, which represent a fixed contribution to Medicare, could not be expected to encourage or discourage use of health care services. Thus, they would not pose a barrier to access to needed services. Hospital coinsurance, on the other hand, could reduce utilization, particularly for those elderly with modest incomes who do not purchase supplementary private insurance. Little is known about what types of hospital stays would be eliminated. There is a very real danger that burdensome hospital coinsurance charges would deter necessary care for many vulnerable elderly and quite obviously they would place serious financial burdens on a chronically ill group of older Americans.

It should also be recognized that since the new premium would replace the current one (set at $203 annually in 1985), many elderly would pay less under the proposal than they do now. The elderly near-poor would pay 2.5 percent of income, with a minimum required premium of $100. Thus, older persons with incomes below $8,000 would be paying a lower premium than at present.

Table VI-2: Distributional Impact of Hospital Coinsurance[1], 1977

Income Class	Hospital Coinsurance Payments as a percent of income of hospitalized elderly
Total	6.4%
Income below poverty level	27.1%
Poverty to two times poverty level	16.2%
2 to 4 times poverty level	6.2%
Over 4 times poverty level	2.2%

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[1] Coinsurance set to yield $5 billion revenues.

Source: Calculated from 1977 National Survey of Medical Care Expenditures, National Center for Health Services Research, U.S. Department of Health and Human Services.

Nearly all elderly would benefit financially from the requirement that physicians accept the Medicare allowable fee. Estimated savings to the elderly are $1.8 billion in 1985 from mandating assignment on physician services to hospital inpatients (HCFA, 1983).

With the improved financial protection afforded by Medicare, many elderly might choose to drop quite costly Medigap supplementary private insurance coverage. An estimated $8 billion is spent by the elderly for such coverage (Senate Aging Committee, 1984).

Cost estimates of the long-term-care component of this proposal are more difficult. The fiscal soundness depends upon the extent to which the coverage is obtained only by those in poor health. It seems that in fact the proposal could have appeal and that nearly all the elderly would opt for the voluntary long-term-care coverage. If so, the projected premium should be roughly adequate to cover the full cost of the coverage -- although the use of general revenues is proposed to pick up the balance should premium revenues fall short of outlays. Some demonstration of this proposal would provide an opportunity to estimate how elderly persons respond to the availability of such coverage.

C. Administrative Feasibility

Administering an income-related premium would represent a major departure from current administrative practice. Any systematic relationship of premiums to income would require administration through the personal income tax system. Even with this approach, however, certain administrative issues are raised. Low-income elderly who do not now file income tax statements would be required to do so under some variations of this proposal. Decisions would be required about the definition of income subject to tax -- social security pensions, tax-exempt bond interest income, etc. The disabled receiving Medicare would need to be identified. Rules governing tax households with both Medicare and non-Medicare beneficaries would need to be designed.

All these issues require resolution but do not represent insurmountable obstacles. Administration through the income tax system would ensure fair and effective compliance without the demeaning administrative procedures that means-tested benefits administered directly by Medicare would entail (Hsiao and Kelly, 1984). It would also not engender the complexity and confusion that varying the benefit package with income would create.

The other provisions of the acute care proposal are relatively straightforward to implement. Current records are adequate to calculate the $1,500 ceiling on out-of-pocket expenditures, with the exception that the elderly would be required to submit verification of prescription drug outlays if total expenditures are near the $1,500 ceiling.

The long-term-care administration would build on the current system. The direct grant program for home help services could use the existing network of voluntary agencies, senior citizens' groups, and community organizations to ensure the availability and delivery of needed home help services. The long-term-care insurance component calls on the administrative expertise embodied in current financing programs for the aged and should be able to maintain the record of administrative efficiency demonstrated by Medicare.

III. Summary

Medicare is extremely important in assuring many vulnerable older Americans of the necessary protection from financial hardship that major illness can bring. It is unthinkable that needed measures to ensure its financial soundness will not be taken. More-effective cost controls and incentives for health care providers than have been instituted to date are vital. Even with such measures, however, Medicare expenditures are likely to continue to outstrip currently expected revenues.

Relying on patient charges for health care services, such as hospital coinsurance, would concentrate payments on the chronically ill, many of whom have extremely modest incomes. Increases in payroll taxes or diversion of funds from general revenues are not promising for the next few years, given major increases in payroll taxes that have already occurred and the unprecedented deficits in the federal budget.

To ensure the financial soundness of Medicare, it seems imperative that a fundamental reform of Medicare's financing be undertaken. The proposal made here is to merge the HI and SMI portions of Medicare, with a combined Medicare Trust Fund financed by currently scheduled HI payroll taxes, general revenues currently projected to meet SMI expenditures, earmarked cigarette tax revenues, and a new Medicare premium related to the income of the enrollee. The flexibility of altering premiums or general revenue support depending upon requirements of the program, the effectiveness of cost-containment measures, and budgetary considerations would be greatly enhanced by a merger of the two parts of Medicare.

Reliance upon a premium that varies with income would guarantee that any financial contribution by those receiving Medicare is equitably borne and does not place a financial burden on any group or person. With an assured, stable funding base, Medicare benefits could be expanded to fill many current gaps in acute and long-term care. Coupled with provider cost controls, such as extension of current limits on hospital payments and physician fee schedules with mandatory assignment, this financing reform could restore Medicare's original promise ensuring adequate health care for all older Americans without the threat of financial ruin.

This proposal requires careful consideration and debate. But it should not be forgotten that many of our nation's most vulnerable citizens depend upon Medicare to live their lives with dignity. These reforms would free them of the worry of financial ruin that major illness can bring, while simultaneously assuring the long-term adequacy and fiscal stability of the Medicare program. In the current climate of fiscal stringency, it is important that we work to protect and improve the essential character of these programs, rather than dismantling a system that has brought much needed protection to older Americans.

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Mr. WYDEN. The members of the second panel will present information on public programs and private initiatives for financing long-term care service. Dr. Judith Feder, codirector, Center for Health Policy Studies at Georgetown University. She is author of numerous studies on Medicare and Medicaid and their role in financing both health and long-term care services. We are also happy to have Teri Louden, president of Louden & Company, a health care consulting firm that has done work primarily in the private sector.

Thank you both very much for appearing before the subcommittee. Today we do have copies of your formal statements which will be included in the hearing record and if you would, we would like to ask you to take no more than five minutes to summarize those statements and then we will have questions for both of you.

Dr. Feder.

STATEMENTS OF JUDITH FEDER, PH.D., CODIRECTOR, CENTER FOR HEALTH POLICY STUDIES, GEORGETOWN UNIVERSITY; AND TERI L. LOUDEN, PRESIDENT, LOUDEN & CO.

Ms. FEDER. I appreciate the opportunity to appear before you this morning. For all but the very rich, paying the bill for extensive long-term care means financial catastrophe. A year in a nursing home now costs about $18,000—almost twice the average income of the Nation's elderly. Even a short stay in a nursing home, say 90 days, costs about $5,000 or half that average income.

The catastrophe associated with the need for long-term care is not simply monetary. People needing care at home face a different sort of catastrophe, the heavy burden they place on family and friends who provide almost all the services they now receive.

While insurance, public or private, is available to protect against other catastrophes like the need for hospital care, we lack both public and private insurance to protect people in need of long-term care.

This morning I will describe to you the public financing we do provide for long-term care and the ways it falls short of true insurance protection.

First is medicare, which does insure the elderly against a large portion of their acute medical expenses.

As you noted, the American Association of Retired Persons recently surveyed its members on issues of long-term care financing. Almost 80 percent of the people who felt they might need an extended stay in a nursing home believed that medicare would pay for it.

As you said, the fact is that Medicare will not pay for it. Elderly people's confusion may result from the fact that Medicare does cover some services from real long-term care providers, skilled nursing facilities, and from some providers incorrectly perceived as providing long-term care, home health agencies. But whomever the providers, these Medicare benefits are short term, not long term.

Although Medicare theoretically covers up to 100 days of care in nursing homes, average benefits, not stays, last about 28 days. Similarly, people receiving home health services typically receive about 23 visits despite potentially unlimited coverage.

Why are benefits so limited? You alluded to that fact earlier. In order to restrict coverage to short-term, postacute care, Medicare includes a number of carefully crafted eligibility requirements: not only the prior stay in the hospital for the nursing home care, but also requirements that people need skilled care, that they need it on a daily basis or demonstrate evidence of rehabilitation potential. For home health benefits, people must be "homebound" and their care needs must be on an "intermittent" basis. Some people who need care never satisfy these requirements and most who do satisfy them only for short periods.

Furthermore, Medicare's limited benefit means limited revenues to nursing homes. Medicare provides so small a share of nursing home revenues that many nursing homes don't participate in the Medicare Program or are reluctant to serve medicare patients.

Medicare's restricted coverage is not a new problem, but as we have heard this morning, the importance of that problem is growing in response to Medicare's new prospective payment system for hospitals. As hospitals discharge patients sooner, more people can be expected to seek nursing home care.

If nursing homes are not willing to provide that care or Medicare doesn't cover it, people will have problems in getting care and in paying for it.

In sum, medicare provides no long-term and limited short-term protection. What about Medicaid?

Medicaid is very valuable to the elderly. To the poor elderly, it fills many of the gaps that Medicare leaves out and for the poor as well as many non-poor elderly it finances nursing home services, but despite this valuable role, Medicaid has significant limitations.

Foremost, Medicaid is not an insurance program. Medicaid does not protect people against financial catastrophe. It finances service after catastrophe occurs. To receive Medicaid benefits, that person must contribute all their resources except $25 a month for the cost of care.

This requirement makes it very difficult for a person who has entered a nursing home to return home and also makes it quite difficult for a spouse to maintain a standard of living or to finance services once care needs arise for that spouse.

Eligibility based on impoverishment is probably the most widely recognized problem with Medicaid, but it is not the only problem.

First, Medicaid is largely a State-designed and operated program and, as a result, protection varies considerably from State to State.

Second, State efforts to contain costs, while understandable, limit service availability. I don't have to tell this committee about the problems people face because most Medicaid programs do not cover in-home and community-based long-term care.

The newly authorized waivers in that area are a new opportunity for States to offer these services, but cost and other constraints have limited the size of these programs and they remain quite small.

Less well known is that cost containment efforts also limit the availability of nursing home care. States limit the nursing home bed supply through direct regulation—certificate of need—or by paying low rates for Medicaid patients. The result is more Medicaid-eligible patients seeking nursing home beds than there are beds to serve them.

Since Medicaid pays less than private patients, nursing homes prefer the private pay and are reluctant to take the Medicaid patients, especially the heavy care patient, the patient who requires the most intensive and costly care. As a result, the patient who most needs the bed has the greatest difficulty finding one.

Although far better than nothing, the last resort approach that Medicaid takes is no substitute for true long-term care insurance. Reliance on individuals' own resources backed up by a welfare-based program, Medicaid, concentrates the financial burden of severe impairment, a largely unpredictable event, on the unlucky few who experience it.

In no other sphere do we require victims to bear the brunt of unpredictable catastrophe. Here as elsewhere, we ought to spread that burden with insurance.

[The prepared statement of Ms. Feder follows:]

Testimony before the
Subcommittee on Health and the Environment
Committee on Energy and Commerce

Judith Feder, Ph.D.
Co-Director
Center for Health Policy Studies
Georgetown University

Mr. Chairman, Members of the Committee, I am Judith Feder, Ph.D., Co-Director of the Center for Health Policy Studies at Georgetown University. Our research has focused heavily on long-term care financing, and I appreciate the opportunity to discuss that issue with you this morning.

For all but the very rich, paying the bill for extensive long-term care means financial catastrophe. .A year in a nursing home now costs about $18,000--almost twice the average income of the nation's elderly. Even a short stay in a nursing home, say 90 days, costs about $5,000 or half that average income.

People who need care at home face a different sort of catastrophe: the heavy burden they place on family and friends. Almost all of the services delivered to people at home come from family and friends rather than hired providers. Although in many cases such caring is to be expected and applauded, it places considerable emotional as well as financial pressure on relatives, many of whom may be older or debilitated themselves.

While insurance--public or private--is available to protect against other catastrophes (like the need for hospital care), we lack both public and private insurance to protect people in need of long-term care. This morning, I will describe to you the public financing we do provide for long-term care, and the ways it falls short of true insurance protection..

Medicare, which insures the elderly against acute medical care expenses, explicitly prohibits coverage of long-term custodial care. The American Association of Retired Persons recently surveyed its members on issues of long-term care financing. Almost 80 percent of people who felt they might need long-term nursing home care believed that Medicare would pay for it. The fact is, it will not.

Elderly people's confusion may result from Medicare's coverage of service from some real long-term care providers (skilled nursing facilities) and from some providers incorrectly regarded as delivering long-term care (home health agencies). Whomever the providers, these Medicare benefits are not long-term care. They are short-term benefits for skilled nursing or rehabilitation services. Although Medicare theoretically covers up to 100 days of care in a skilled nursing facility, the restriction of coverage to skilled care means that, on average, people receive Medicare benefits for only 28 days. Similarly, Medicare's home health benefit provides an average 23 visits per person, despite potential coverage of 200 visits per person before 1981 and, today, potentially unlimited coverage.

Why are benefits so limited? In order to restrict coverage to short-term, post acute care, Medicare includes a number of carefully crafted eligibility requirements. For nursing home benefits, requirements include a need for daily skilled care or evidence of "rehabilitation potential." For home health benefits, people must be "homebound" and their care needs must be "intermittent." Some people who need care never satisfy these requirements, and most who do satisfy requirements do so only for short periods.

The termination of Medicare benefits does not necessarily mean an end to patients' service needs. What ends is the narrowly defined need for skilled care on which Medicare coverage depends. Need for service may go well beyond that point. The average Medicare patient stays in the nursing home 30 days beyond termination of Medicare coverage. Need for home care may also continue beyond termination of coverage, although there is not information to confirm this.

As a result of benefit limitations, only about 4 percent of Medicare spending, about $2.5 billion, goes to Medicare benefits for skilled nursing care and home health. Furthermore, Medicare provides such a small share of nursing home revenues that many nursing homes are unwilling to participate in the Medicare program or to serve Medicare patients.

Medicare's restricted coverage is not a new problem. But its consequences are growing more significant under the new hospital prospective payment system. As hospitals respond to that system by discharging patients sooner, more people can be expected to seek post-hospital care. If nursing homes are not willing to provide that care or Medicare does not cover it, beneficiaries will face problems in getting care and in paying for it.

Basically, then, Medicare provides limited insurance protection against short-term needs for skilled nursing or rehabilitation care. It provides no long-term protection. How well does Medicaid fill the gap?

Medicaid is very important to the elderly in two respects. First, for the poor elderly, Medicaid provides acute care benefits that Medicare leaves out--most importantly, benefits for prescription drugs. Second, for the poor as well as many non-poor elderly, Medicaid covers nursing home care. More than a third of Medicaid spending goes to the elderly, primarily for nursing home care, and Medicaid provides nursing homes about half their revenues.

Despite Medicaid's value, its limitations are numerous. Medicaid is not an insurance program. A means-tested program, it offers benefits to the very poor and to people who become impoverished because of the care they need. In other words, Medicaid does not protect people against financial catastrophe; it provides care after catastrophe occurs.

To become eligible for Medicaid, a person must contribute all resources (except $25 per month) toward the cost of care. This may not be unreasonable for a single individual becoming a permanent resident in the nursing home. But the contribution Medicaid requires is clearly a problem to a person who might be able to return to the community after a nursing home stay or to a person whose spouse depends on shared income and savings and remains at home. That spouse must live near the poverty level and contribute most savings to support the nursing home resident. For many this will not only involve a substantial decline in standard of living, but will also reduce the resources available to finance their present or future care needs, and may even threaten their ability to remain in their homes.

Eligibility based on impoverishment is Medicaid's most widely recognized, but not its only, limitation. Medicaid is a program that is in large part designed and operated by the states. Hence, protection varies considerably from state to state. In addition, state efforts to contain costs, greater in some states than in others, limit service availability.

As the Committee well knows, most state Medicaid programs do not cover long-term care in the home on a statewide basis. States are justifiably concerned that broader benefits will increase, not reduce, total costs. As a result, many people go without needed care or rely on their families--at excessive physical and financial cost--to provide the care they need. Congressional authorization of home and community-based waivers offers states a new opportunity in this area. But cost concerns and other constraints have kept these program quite small.

Less well-known is that cost containment efforts also limit the availability of nursing home care. *States have attempted to control* nursing home costs which absorb more than one-third of their Medicaid budgets by limiting the supply of nursing home beds, either by paying low rates for Medicaid patients or by invoking certificate-of-need regulation to prevent expansion. The result is more Medicaid-eligible patients seeking nursing home beds than there are beds available.

By limiting the total bed supply, states create a "seller's market" and nursing homes can favor more profitable over less profitable patients. Nursing homes prefer private-pay over Medicaid patients, who pay less than private rates, and also choose among Medicaid patients. Because most Medicaid programs do not vary rates sufficiently to reflect differences in patients care needs and care costs, nursing homes prefer patients who need less care. It is the Medicaid patient in need of the most intensive nursing home care--the patient most appropriately placed in a nursing home--who has the hardest time finding a bed.

Although far better than nothing, the last-resort approach that Medicaid offers cannot substitute for true long-term care insurance. Reliance on individuals' own resources, backed up by Medicaid, concentrates the financial burden of severe impariment--a largely unpredictable event--on the unlucky few who experience it. In no other sphere do we require victims to bear the brunt of unpredictable catastrophe. Here, as elsewhere, we ought to spread that burden with insurance.

Thank you for the opportunity to appear before your Committee.

Mr. **Wyden**. Thank you.
Ms. Louden.

STATEMENT OF TERI L. LOUDEN

Ms. **Louden**. I am not sure I represent either a black or a white hat, being from the private sector for these panels. I guess I am going to talk about what you call the missing piece of long-term care. The private sector is definitely not absent from long-term care. As a matter of fact, I think when I go through some points, you will see that they are probably looking at this market as one of the most attractive markets that they have right now.

The first thing I would like to do is define long-term care from the private sector perspective. Do you both have a copy of my testimony? Would you look at exhibit 1. I think it is after page 2 in the front there. I put this together to try to show the vast array of products and services and the way the private sector looks at long-term care is much, much broader than what we have talked about today already.

The private sector looks at the 50-plus, the 50-plus is called the gold-and-gray market, and for those of you that have been reading any of the business press, you will see that it is a very attractive segment for consumer product companies as well as health care companies today. This exhibit shows the continuum of care.

On the left-hand side is what we call enhancing quality of life, everything from Sears-Roebuck, who is offering mature outlook for $7.50 a year to the elderly so they can get discounts on all of their travel and leisure, as well as if you look at HCA which has recently signed a contract with Sears in order to be able to provide discounts on outpatient diagnostic testing. This is the well elderly and is a large and growing market.

You can see the other end to what you defined as long-term care and that is called maintenance. What the private sector does is look at this entire spectrum and then segments. I think someone talked before about looking at different subgroups. In the private sector, it is called market segmentation and that is what they are doing.

The groups on the left-hand side are what they are looking at. What types of companies and organizations do you really define as private? I think that is important because private sometimes means only for profit and that is not true. The private sector includes an enormous volume of hospitals today and nursing homes who are not for profit.

So if we look at the types of organizations that are providing private long-term care, we have hospitals, we have nursing homes, we have home health care, both for profit and not for profit. We have health care companies as well as a vast array of consumer product companies. We even have my company.

We basically came into the market to provide information on a market where there is no information. There is no information on this market. It is a very undefined market. You can't pick up Advertising Age and read about the buying habits of this market. It is not there.

We actually conducted the first national survey on home health care just to be able to find out what figures and consumers and everybody thought about it and we fed that back to our private sector clients. You see, there is an incredible array, hotel chains, you have read about what Marriott is doing in long-term health care, the health clubs and fitness centers, massive amounts of effort being placed on fitness for the elderly.

Chicago is having the Americas Marathon on Sunday. There is a senior citizens club in the Metropolitan Chicago Coalition on Aging and we are sponsoring all kinds of activities for seniors around it.

So there is a whole array of different organizations. I think it is important to look at it and say that the private sector sees this as a tremendous growth opportunity. It is the fastest growing market in this country and for anybody that has ever worked in a corporation or in a business that represents opportunity and that is what they are looking at but again they are segmenting.

Another thing important to look at is which products and markets is the private sector really looking at targeting. Let's break it down into the for-profits and the not-for-profits. For-profit companies are in the business to make money. They are not in the business to provide things that break even.

So, therefore, they are obviously looking at those products and markets which are large, which are growing, and which can provide them with a return on investments. That return can be provided by those individuals who can pay privately or have insurance that is attractive from a coverage standpoint.

Not-for-profits, including many hospitals, have a twofold mission. One is obviously in the past to serve the needs of those who are sick and in need of health care. Unfortunately, in today's market with the introduction of Medicare prospective payment and with the increased competition in the market, hospitals, nursing homes, home health agencies who used to be not for profit cannot afford to serve only the indigent.

They develop what we call a portfolio approach. The portfolio says, "I can serve the indigent only if I can serve those who pay. If I am going to get a 10-percent negative return on one end, I have to get a 10-percent positive return somewhere else in order to offset it."

Even the Catholic hospitals who have been serving the indigent elderly are calling us and saying how do we develop strategies so that we don't lose money in this business because we can't afford it anymore.

Another key market is the children of the elderly and I think that is a market that you can't overlook. The children very much pay for many of the services of their parents. They pay for long-term care insurance. They pay for all kinds of services. A new service to open in New York City costs $125 a month and if you don't live in New York City and you live further away, you can have someone checking up on your parents and helping them with medicare questions and admitting them and looking at nursing homes and home health agencies to check the quality.

I would pay for that service. That will be a growing service in this country and it is paid for by the children. What are the hospitals and nursing homes getting into, everything from day care to housing to home health care and then you have the growing home health care market.

I recently attended the National Association for Home Care Convention. It was interesting to note that there were 5,000 attendees; 5,000. That is as big as the American Hospital Association Convention, which is all hospitals. So we see that the private sector is definitely involved.

Another thing I would add is that the private sector is targeting what we call the young-old and they are also targeting this gold and gray market.

Let me give you some examples.

I have a pamphlet here from Campbell Soup, "Better Life Guide No. 4, *Fitness Over 50*". It goes on—it is a nice little booklet—they have a whole series of these. They are seeing this as a very attractive market for them.

I have another incredible ad, this was in the Wall Street Journal. This is an ad by Aetna Insurance——

Mr. **Wyden**. Excuse me. If you have an extra copy, we would very much like to have those for the record.

Ms. **Louden**. Sure.

Mr. **Wyden**. Let us make a copy so we can have one for the record and you will have the original.

Ms. **Louden**. Sure.

This ad is from Aetna Insurance, and I think it is interesting to note the title, is "Life at the End of the Earning Curve". It has a chart here and at age 60 it has your earning curve drops and then it says on the bottom, "You grew up unsure you would see 60 yourself. Now you intend to attend your childrens' 60th birthday parties. Aetna has developed a range of sophisticated insurance and financial services for the generation approaching retirement today".

So what you are talking about with long-term care insurance some of these places are already looking at it and it is interesting how they are targeting the market.

Another article I had out of Fortune magazine to show that the private sector is, I think, willing if given the proper incentives "the over-50 crowd is almost as numerous as baby-boomers, 62 million versus 68 million, and it has much more money, controlling 50 percent of discretionary income in the United States, 77 percent of financial asssets, the over fifties represent a $800 billion a year market and their numbers are expanding."

Again, the over 50, that is what they are looking at. They are not looking at the 85 and over, I can tell you.

What are the particular markets that are not being served by the private sector? Well, obviously they are not going to be looking at those that are unable to pay and who are they? Those are the old, old as the private sector might segment them and that is your 85 and over, or those that have depleted their resources, those that are frail and dependent and don't have the ability to pay, they are typically individuals, woman and minorities.

The attractive are obviously the young-old, families, those that have children who are fairly well to do who will pay and those who are white and male, and I say that being a woman. I was hesitant on whether I was going to bring this up, but the average poverty for 65 and over is 15.3 percent. The average poverty rate for white men over age 65 is only 6.5 percent. It is all those women, Spanish, black, they are a lot of the people that the private sector looks at and says gee, it would be great but they are poor and we cannot serve them.

Finally, I would just like to say that the private sector in looking at the whole area of the elderly and long-term care is very much concentrating on wellness. There is a big move in this country to keep people well and in doing so, they are going to create massive problems for the public sector, because the longer you keep people alive and you keep them well, they are well at age 65 and 75 and they have money and they pay the private sector.

By the time they reach 85 and 90, they belong to you because they don't have money. At that point, there are God-given diseases that just come. I don't care how much you run and I think Dr. Rowe can probably address that in some of the things he talks about, so I guess I would like to see the public sector take a lesson from the private sector.

I would like to see you segment the over 65, the over 85, look at the elderly market, segment it and serve those areas without duplication of effort of what the private sector is already doing.

Thank you.

[Testimony resumes on p. 106.]

[The prepared statement of Ms. Louden and attachments follow:]

TERI L. LOUDEN
LOUDEN & COMPANY
CHICAGO, ILLINOIS

Teri L. Louden is the founder and President of Louden & Company, a health care consulting firm specializing in strategic planning and marketing for a wide variety of health care companies and organizations. Since its founding three years ago, the firm has quickly developed a national reputation for its work in the home health care and older adult markets. In addition to its consulting work in these areas, the firm has developed a series of national seminars and publications which provide information on these key markets.

Ms. Louden is well known in the industry for her many national presentations and published articles on leading-edge health care topics. Prior to starting her own firm, whe was Manager of Corporate Planning at American Hospital Supply Corporation, held positions in sales and marketing at Baxter Travenol Labs, and was a health care consultant at Booz, Allen & Hamilton. She is a Board Member of the Metropolitan Chicago Coalition on Aging and has participated on numerous national panels and task forces addressing long term care issues. Her educational background includes an MBA from the University of Virginia and a B.S. in mathematics from North Carolina State University.

This presentation will address five major questions regarding the private sector's role in providing long term care:

1. How does the private sector define long term care?
2. What types of companies/organizations in the private sector are involved in providing some aspect of long term care?
3. Which long term care products and markets is the private currently sector serving and targeting?
4. Which long term care products and markets are not being served by the private sector?
5. What are the implications of these findings for meeting our nation's long term care demands in the future?

1. How Does The Private Sector Define Long Term Care?

The term long term care has many meanings, and, as yet, there is no one standard definition for this particular market segment. Defined narrowly, it includes only care of the chronically ill. However, a broader definition includes a much wider population group and a larger array of products and services--from prevention and diagnosis to care of the chronically ill.

The Private Sector Defines Long Term Care Broadly, and Then Segments The Market.

The private sector is used to defining broad markets, and then segmenting those markets into categories so they can be further analyzed and targeted as approrriate. To the private sector, long term care is not just nursing homes, but a vast array of products and services which can be effectively marketed to the older adult population.

Such Products and services can be viewed along a continuum of care, as shown on Exhibit 1.

Exhibit 1

Long Term Care Be Can Be Viewed As A Continuum of Care

Continuum of Care Segments

Enhanced Quality of Life	Prevention/ Diagnosis	Outpatient Programs	Treatment - Inpatient	Rehabilitation	Maintenance
• Adult Education	• Self-Care Products	• Outpatient Testing/ Screening	• Geriatric Inpatient Programs	• Rehab Facilities	• Nursing Homes
• Retirement Counseling	• Self-Testing Products	• Geriatric Outpatient Programs	• Self-Care Units	• Home Health Care	• Caregiver Programs
• Financial Counseling	• Exercise/ Fitness	• Elderly Day Care	• Inpatient Rehab Units	• Outpatient/ Rehab Therapy	• Hospice
• Retail Products	• Nutrition Counseling	• Outpatient Rehab/Pain Programs	• Inpatient Psyche Units		• Pain Management
• Travel Leisure	• Health Education		• Hospital - Based SNF		• Family Counseling
• Support for Caregivers	• Hearing/Eye Testing		• General Inpatient		
• Housing/ Retirement Living					

Source: Louden & Company

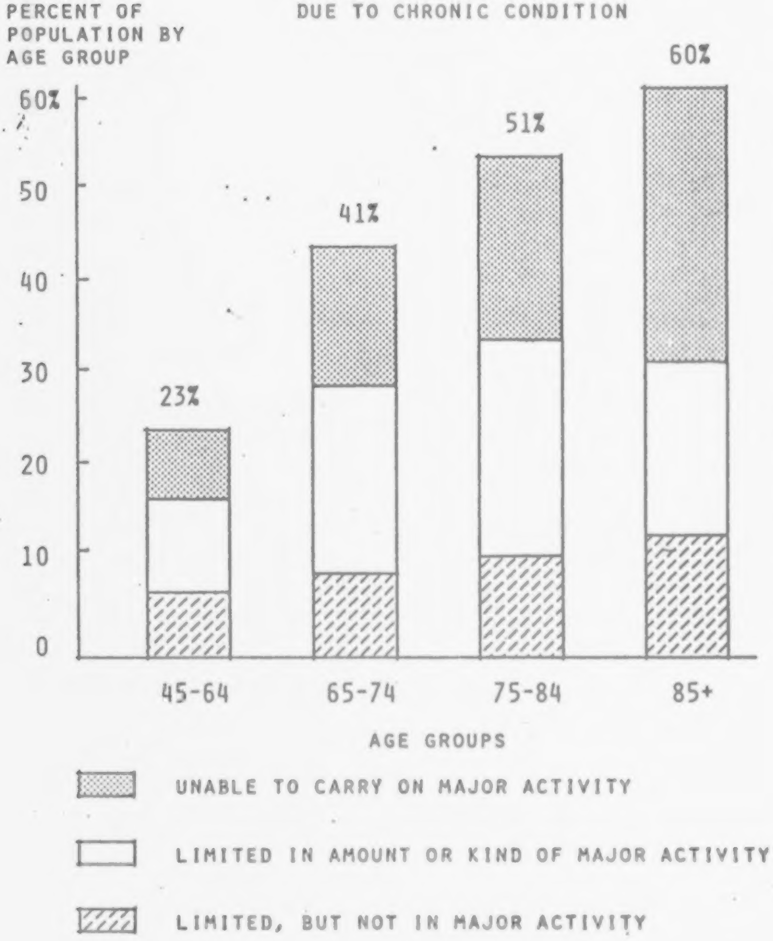
The Private Sector Defines Long Term Care As Being Products And Services To Assist Both Those Who Are Independent As Well As Dependent.

The private sector looks beyond the chronically ill for long term care, including also the well-elderly and those with only a limited need for assistance. By defining the market more broadly, they can expand the size of the markets they serve and attract a more financially viable customer group.

Exhibit 2 shows an analysis of elderly functional limitations by age group. The private sector is more likely to target those who may need some assistance but are not totally dependent on others for financial support and daily living assistance.

Exhibit 2

PERCENT OF ELDERLY WITH LIMITATION OF ACTIVITY DUE TO CHRONIC CONDITION



SOURCE: 1979 SURVEY OF NONINSTITUTIONALIZED ELDERLY, NATIONAL CENTER FOR HEALTH STATISTICS

2. What Types Of Companies/Organizations In The Private Sector Are Involved In Providing Some Aspect Of Long Term Care?

There are a wide variety of organizations providing long term care products and services.
Some are for-profit companies, while others are not-for-profit (but non-governmental) organizations. Some are health care providers, while others are in non-health businesses, but recognize the growing market for older adult products and services. And, there is a growing base of entrepreneurial businesses who are seeking to enter the growing market for long term care services.

Exhibit 3 shows the wide range of private organizations involved in providing some aspect of long term care. Their strategies and type of product/service offerings obviously vary depending on the type of organization and their own particular goals and objectives.

Exhibit 3

Types of Private Sector Organizations Involved in Some Aspect of Long Term Care

Health Care Organizations

Independent Hospitals

Multi-Hospital Systems (for profit and not-for-profit)

Hospital Affiliated Networks

Nursing Homes and Chains

Home Health Agencies

Durable Medical Equipment Companies

Private Duty Nursing Agencies

Pharmacies

Health Insurance Companies

HMO'S

Private Clinics

Medical Product Companies

Non-Health Care Organizations

Hotel Chains

Retirement Home Developers

National Department Store Chains

National Associations for the Elderly

Health Clubs/Fitness Centers

Employers (funding)

Travel Agencies

Private Foundations

Consumer Product Companies

Churches

Community Organizations

3. Which Long Term Care Products and Markets Is The Private Sector Currently Serving And Targeting?

The particular long term care products and markets served by the private sector varies by organization.

For-profit organizations are obviously most concerned with targeting those markets which will produce an acceptable level of financial return. Not-for-profit organizations are more likely to try and serve both: 1) those markets which will produce an acceptable level of financial return and 2) those who are in need but cannot provide satisfactory financial returns. While not-for-profit organizations will still try to provide long term care for low income groups and the indigent, recent government reimbursement pressures and the competitive health care environment have greatly expanded their need to also develop profitable businesses to offset their loss of income from previous sources.

Average hospital occupancy levels have fallen from 72% in 1983 to 60% today. And, the average length of hospital stay of medicare patients is now 7.7 days compared to 9.5 days in 1983. As a result, even not-for-profit hospitals cannot totally serve the nations's long-term helalth care needs without seeking some profit potential to help offset the effects of declining inpatient revenues. Even Catholic hospital systems, with missions to serve all those in need, are being forced to develop profitable long term care programs to offfset those which produce no income or operate at a loss.

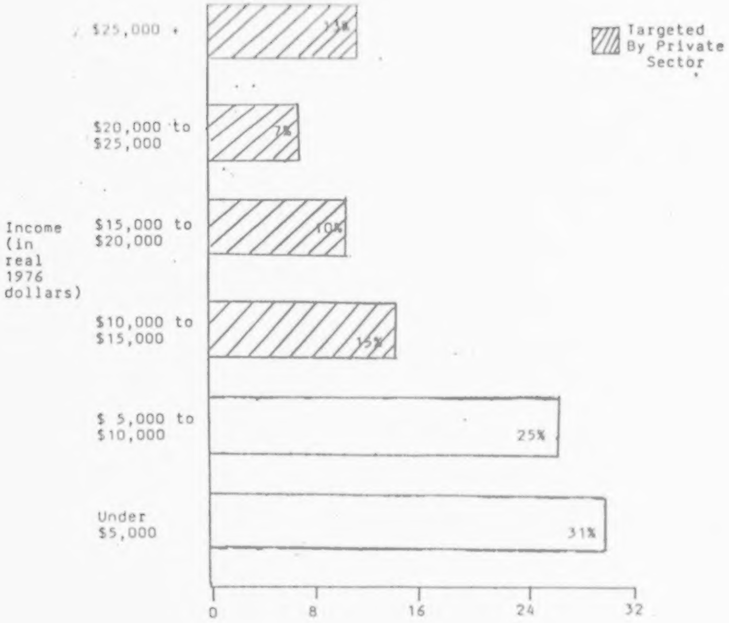
As A Result, The Primary Long Term Care Markets Targeted By The Private Sector Are Those Which Can Provide Appropriate Financial Returns.

Private sector organizations are most likely to target products and services to those elderly populations who are adequately covered by insurance or can self-pay. Obviously, those having medium to upper income levels and assets are most attractive. And, the children of the elderly also represent an attractive market for the private sector since they are likely to have the financial resources to pay for parental care, and often feel the "guilt" of needing to do so.

Exhibit 4 shows a projection of those income segments of the over 50 population most likely to be targeted by the private sector. Note that I have chosen the over 50 population, as the private sector is increasingly looking to this group since their average financial resources are attractive from a marketing perspective.

Exhibit 4

The Over 50 Population Segments Targeted By The Private Sector



Source: Statistics from Data Resources, Inc.

The Private Sector-Is Marketing A Variety Of Products And Services To Those Older Adult Groups Who Can Pay

A variety of products and services are being provided by the private sector for those elderly who can pay directly or who have insurance reimbursement or the financial support of their children. Some examples include:

- Retirement and life-care communities operated by hotel chains, hospitals, and other organizations
- Specialized supplemental and long term care insurance packages
- Luxury nursing homes
- Special elderly and retiree clubs to provide discounts on insurance, retail products, travel, financial services, etc.
- Sports fitness, nutrition, and other "wellness" programs for older adults
- Private duty home nursing, aide, and chore services
- Travel Packages designed by hotels, airlines, and tour planners
- Special restaurant and meal programs
- Financial counseling services

o

Currently, there exists a great deal of fragmentation in the system, as no one coordinates all of the many programs available.

The Growing, Affluent, "Young-Old" Represent An Increasingly Attractive Market For The Private Sector.

A recent article entitled The Gold and The Gray in Fortune Magazine cited the following:

"The over 50 crowd is alsmost as numerous as the baby boomers - 62 million vs. 68 million. And, it has much more money. Controlling 50% of discretionary income in the U.S. and 77% of financial assets, the over-50's represent an $800 billion-a-year market. And their numbers are expanding."

Needless to say, the private sector sees the growing affluent elderly as a potentially untapped market, ripe for development.

However, the attractive financial dollars being targeted are not held by all those over 50. For those fortunate enough to have financial resources after age 50, the private sector is clearly going to be there to provide whatever products or services are needed, be they health care, retail, housing, or social support services. For those not having the financial resources to partake of this "Golden Age" marketing boom, the outlook is not particularly bright. The following pages describe the elderly segments who are most likely not to be served by the private sector.

Exhibit 5

Estimate of Private Sector Views of Attractive vs. Unattractive Older Adult Segments

Attractive	Unattractive
"Young-old"	"Old-old"
Well	Frail, dependent, mentally ill
Families	Individuals
Middle to upper income (most likely to be families, white and males)	Low income (most likely to be individuals, women, and minorities)

While there are obviously exceptions to the above, in general the unattractive segments offer little financial return incentive for private sector involvement.

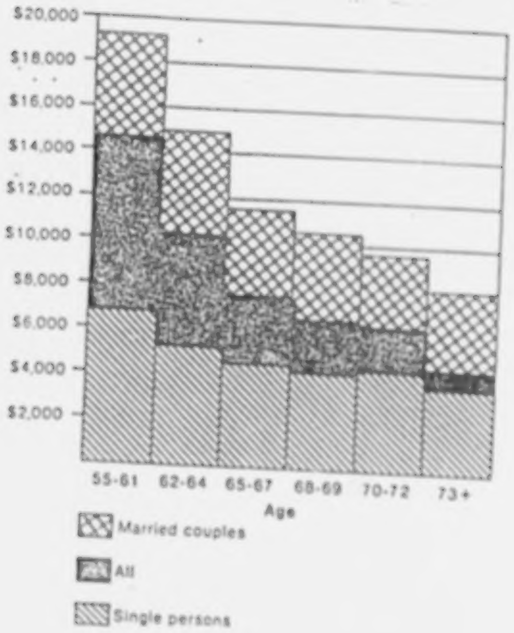
The "Old-Old" Are Typically Not Targeted By The Private Sector As Being Part of The Attractive "Gold and Gray" Market

As our population's life expectancy has increased, so has the number of individuals over age 85. And, this segment is expected to be the fastest growing segment of the entire U.S. population in the coming decades. From 2.3 million over age 85 today, forecastors predict this group will nearly double by the year 2000, reaching 5.1 million.

Unfortunately, while we have increased the numbers of older adults living longer, we have not necessarily made it possible to extend the healthy years for a significant portion of the "old-old." As a result, the over 85 group often suffer from multiple health problems, and find their income sources gradually being depleted. Exhibit 6 shows the declining income of the elderly as they increase in age. Also note that single persons are more likely to have low incomes in all elderly population groups.

Exhibit 6

Median Total Monthly Income of the elderly - 1978



Social Security Bulletin, December 1981/Vol. 44, No. 12

Elderly Women and Minorities Also Represent A Less Attractive Market For The Private Sector.

Segmentation of the poorer groups of elderly also reveals a large portion of single females and minorities. Exhibit 7 shows the higher poverty rates among elderly women and minorities.

Exhibit 7

Poverty Rates For Elderly Men, Women, and Minorities

Above Average — 6.5% White men below average 65 +

Average for 65 + = 15.3%

16.2% White women 65 +

23.6% Spanish men 65 + above average

Below Average — 27.4% Spanish women 65 +

32.3% Black men 65+

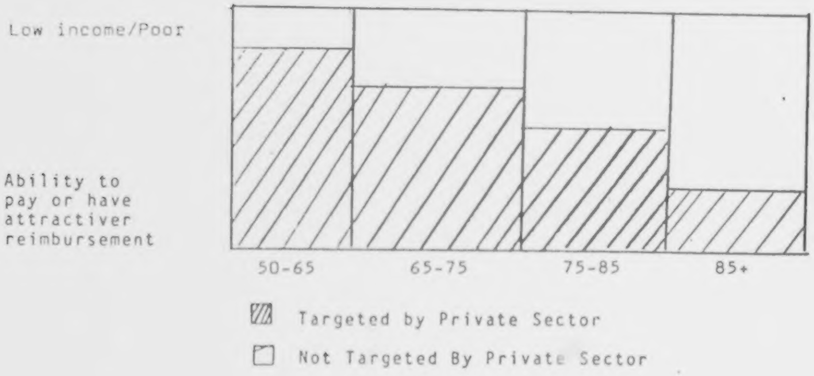
43.5% Black women 65 +

In Summary, The Increasing Elderly Population Has Expanded Opportunities For The Private Sector, But They Can Only Be Expected To Serve Selected Segments Which Are Financially Attractive.

Exhibit 8 shows a schematic diagram of those elderly segments which are most likely to be served by the private sector. Obviously, those not served will need to be provided for by public sector initiatives or else they may be totally neglected.

Exhibit 8

Older Adult Segments Targeted and Not Targeted By The Private Sector



4. Which Long Term Care Products And Markets Are Not Being Served By The Private Sector?

As the private sector seeks to target attractive older adult markets, they necessarily look at income levels. In so doing, a number of older adult segments appear to be particularly unattractive to serve, and will need to depend on public sources for support and assistance.

Exhibit 5 showed a summary of attractive vs. unattractive older adult markets for the private sector. It should be noted that those considered unattractive fall into two major categories: 1) Those unable to pay out-of-pocket 2) Those depending on public aid and medicaid reimbursement which is less than adequate for private sector desired returns.

5. Implications For Future U.S. Long Term Care Demands

Through technology advances and increased prevention and early diagnosis of illness and disease, we have been able to greatly prolong the average years of life within the U.S. However, with this prolonged life has come a new dimension of long tem care needs--rehabilitation and maintenance of chronic illness gradually replacing acute disease. Not only does this process require greater and more prolonged health care, but it also creates greater financial dependency among the "old-old."

The private sector uses a process of market segmentation to target growing elderly groups with attractive financial resources to pay for products and services. This in itself is positive, as these individuals can expect an increasingly wider array of available programs resources made available to them.

But, what about the elderly segments who are not able to pay? Or those whose insurance or public reimbursement coverage is so low that only minimal (and often inadequate) support services are available? Who will take care of this growing population group?

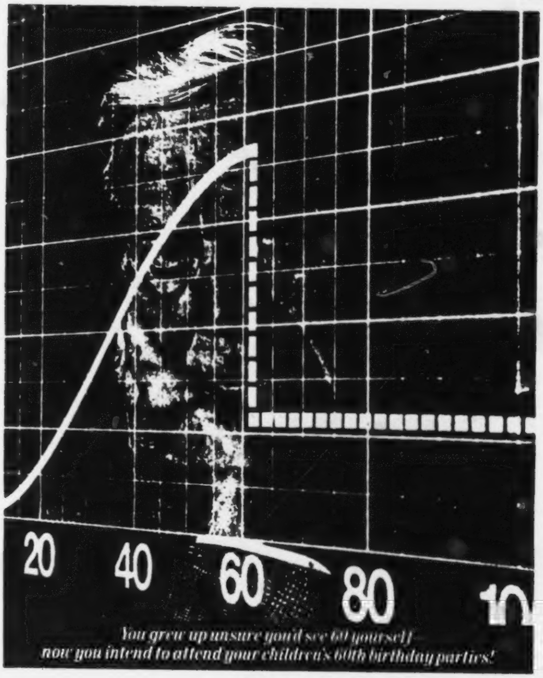
For the public sector to meet the needs of this underserved population, several recommended actions seem appropriate:

- The public sector must also segment the older adult market, just as is done by the private sector. However, their focus will be on finding those segments which are likely to be underserved by the private sector in future years.

- The public sector should avoid duplication of targeted financial support to those elderly segments already being served by the private sector. Since all segments cannot be served adequately, efforts should be placed on supporting the low income groups of the "young-old", and a higher proportion of the "old-old" who are in greater need of assistance.

- Efforts should be considered to support private sector attention to current "nonattractive" elderly groups. However, care is necessary to avoid inadequate reimbursement which will force the private sector to withdraw support. An example of this is the recent squeeze on medicare home health care reimbursement which has already forced the withdrawal of several major pirvate home care companies from this market. Instead, they are refocusing on their more attractive private duty home care service business.

Life at the End of the Earning Curve



You grew up unsure you'd see 60 yourself—now you intend to attend your children's 60th birthday parties!

Ætna has developed a range of sophisticated insurance and financial services for the generation approaching retirement today. Don't get caught in the gray area where employee coverage peters out: talk to Ætna today.

SUBJECT: Post-retirement financial planning.

KEY ISSUE: Conventional planning made obsolete by longevity explosion. Even top-echelon earners now face real possibility of outliving resources. Insurance input, investment input, money-management input all crucial. Ætna Life & Casualty strongly equipped to coordinate all three.

DISCUSSION: Ætna manages $30 billion in pension funds, has unmatched experience in retirement financial planning. Ætna IRAs offer a wide range of options (common stock funds, bond funds, etc.), each managed by skilled investment specialists. Ætna can set up a money market fund out of which all insurance premiums are paid automatically...design a health insurance plan to dovetail perfectly with Medicare when it kicks in...tailor an annuity to help deal with tax consequences of selling a home...credit you with a full line of discounts (10% reduction for drivers over 50, for example) in auto and homeowners policies—credits earned over a lifetime of responsibility.

NEXT STEPS: See your local Ætna agent or call a nearby Ætna office. You're going to have a lot of years to be glad you did.

MAJOR INSURERS MOVING ON LONG TERM CARE INSURANCE

According to an article in the August 8th edition of Business Week magazine, only about 100,000 or fewer Americans have long term health care insurance to cover nursing home bills, but that's about to change with a number of big, private insurance firms moving in on the market. Aetna, Metropolitan Life, AIG and Prudential "will start offering long-term-care insurance this summer and fall, entering a market they estimate will total $3 billion to $5 billion within five years. (The) Blue Cross and Blue Shield Association is considering the move." The cost of long-term care is straining families and governments as the population of the elderly, 65 and over, continues its rapid growth. "Long-term care insurance promises at least the start of a solution. The challenge is designing a product that is both profitable for the insurer and affordable for the elderly."

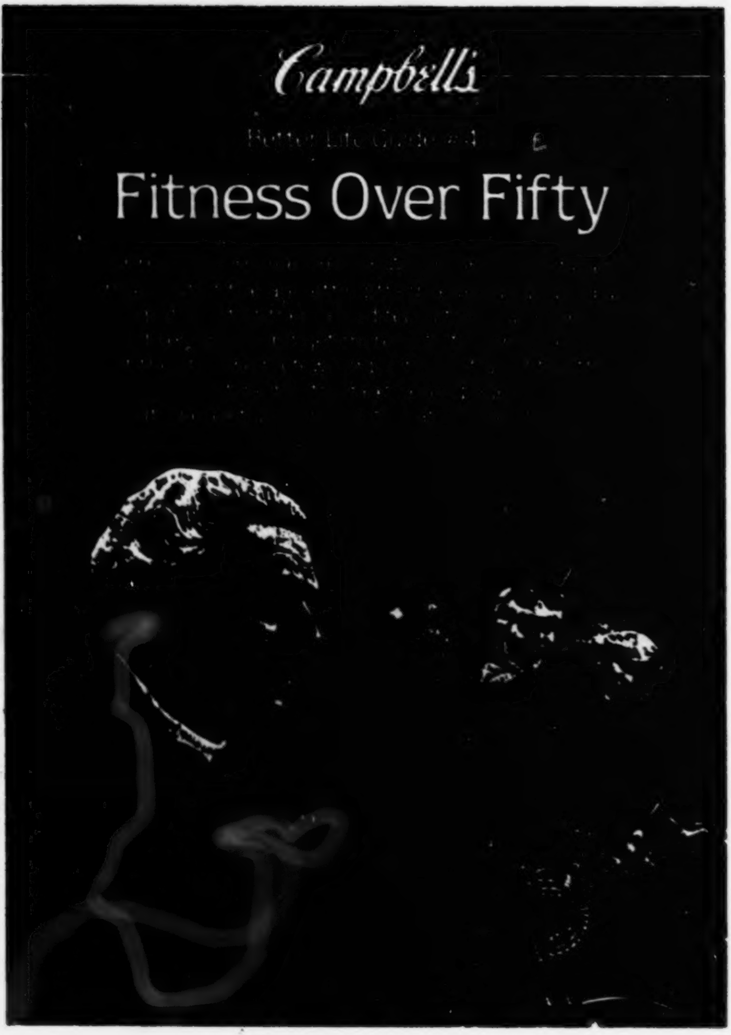
HEALTH CARE CHAINS MOVE INTO INSURANCE BUSINESS

Several large national health care provider chains are moving into the insurance business, making them both providers of and insurers for health care services. National Medical Enterprises (NME) has announced the purchase of Assured Investors Life Company of San Francisco for an undisclosed amount. A spokesman said the acquisition will allow NME to underwrite preferred provider organizations in a number of states, including Arizona, California, Colorado, Kansas, Louisiana, Mississippi, Nevada, New Mexico, Oklahoma, Oregon, Texas, Utah and Washington. A license in Florida is pending. Hospital Corporation of America (HCA), the nation's biggest for-profit hospital chain, says it will begin marketing group health insurance and a preferred provider hospitalization plan in three cities this month. A spokesman said both plans will be offered in the Nashville and Chattanooga, Tennessee, and Charleston, S.C., markets, with sales efforts expanding to 15 to 20 additional cities within 18 months. NCA got into the insurance business by acquiring New Century Life Insurance Company in April 1985.

American Medical International (AMI) launched its own health insurance product, AMICARE, in June 1985 in Florida. AMICARE is a combination of products, including an insured PPO, claims administration for self-insured employees, and tailor-made plans for large employers. In late 1984 AMI purchased Fidelity Interstate Life Insurance Company (Los Angeles, CA) which is licensed to sell health insurance in 45 states and Washington, D.C., and this acquisition forms the basis for the AMICARE package. Humana Corp. (Louisville, KY) also is engaged in marketing health insurance.

The Voluntary Hospitals of America -- a group of 450 hospitals -- and Aetna Life and Casualty Company have agreed to a joint venture through which they will offer health insurance. The new venture, Voluntary Health Plans of America, will move the nonprofit hospitals into competition with their for-profit peers -- Hospital Corp. of America, Humana and others -- which have already entered the market. Officials involved in the joint venture said it would become operational this winter and they expect to have 5 million to 10 million subscribers within five years. Blue Cross and Blue Shield Association President Bernard R. Tresnowski commented that the hospital chains are simply "using insurance to market their product and fill their beds," in an August 12, 1985 New York Times article.

To remove and save this booklet, tear along perforated line.



Campbell's

Better Life Guide #4

Fitness Over Fifty

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Four common excuses for not exercising after 50

"Most of us don't wear out, we rust out," says a U.S. Health and Human Services booklet for older Americans. "The way to **keep** lively is to **be** lively: the way to stay active is to move."

And the best way is to exercise as regularly and vigorously as our doctor, capabilities and infirmities will permit.

Yet a sizeable majority of Americans 50 and over shun exercise the way a cat shuns water. A recent poll says only 30% of Americans aged 50-64 exercise strenuously three times a week, and only 22% of those 65 and over.

Some of the best things in life ride on physical fitness. These include resistance to such crippling disorders as heart disease, joint and muscle ailments—disorders an inactive lifestyle often contributes to. They also include the ability to handle stress; self-esteem, length of life itself. Why are so many of us letting ourselves rust out?

Here, according to fitness expert C. Carson (Casey) Conrad, are the four most common excuses older people give for not exercising:

1. **"I don't need it."** This person tells himself (herself) that his need for exercise decreases as he grows older. Not so. To keep from rusting away, that's when he needs it most.

2. **"It's too risky. I might get hurt."** True, but you can get hurt getting out of bed. Older people, Conrad found, "vastly exaggerate" the perils involved in vigorous exercise. It makes it easier to say, "Switch to Channel 2, dear. Let's see what's over there."

3. **"I mow the lawn every week"**—or, "play weekend tennis"—"so I'm keeping in shape, right?" Wrong. Men and women over 50 tend to overrate the benefits of such "light, sporadic exercise."

4. **"I'm too old for that kind of stuff."** Most older people, Conrad says, habitually "underrate their capabilities." In contrast, there are the active, the alive, the alert—doing the best they can, and enjoying life.

We can go either way. It's just a question of how we want to live—and how long.

What does happen as we grow older?

Aging, like birth and death, is an inescapable factor of being alive. It's the road we travel from one to the other. To a fading movie star, it may spell tragedy. To George Blanda, durable pro-footballer and author of **Over Forty**, age is "only a number…an attitude."

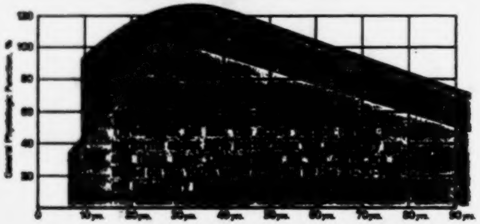
For genetic and other reasons, individuals age in different ways, at different rates. But on average, these are some of the changes along the way:

Our growing years take us to physical maturity at about 30. There the curve turns gradually down. Between 30 and 70-75, in both men and women, muscle mass and strength decline by 25-30%. Vital lung capacity decreases by 40-50%. Liver and kidneys lose 40-50% of their functions. Diminishing female bone mass begins at 35-40; by 70, it may reach as much as 30%; in males it starts at about 50, may reach 10-15% at 70. Body fat tends to increase. Heart output declines; blood pressure may rise. Nerves transmit signals more slowly, so our responses lag. Joints stiffen; we lose flexibility.

The physiological effect? The news is bad and good. The Euro-American Curve* (it applies to most industrialized societies) depicts our work capacity, or ability to function within our environment. It closely parallels our body's aging process, rising to a peak of about 100% in the first 30 years, then declining at about 1% a year.

But there are **two** curves: At all points of the uppermost curve, people who keep moving, who exercise, turn in a performance 20% better than those on the lower curve, the people who aren't active. From 30 on, the doers aren't youngsters any more—but they're staying young at heart.

The Euro-American Curve



*Exercise and Aging: The Scientific Basis, edited by Everett L. Smith and Robert Serfass, copyright © 1981 Enslow Publishers, Inc., Box 777, Hillside, NJ 07205. ($16.95 plus $1.50 postage and handling.)

Middle-age/senior fitness: The exercise imperative

"If exercise could be packed into a pill," says Dr. Robert N. Butler, national authority on aging, "it would be the single most prescribed and beneficial medicine in the nation." Meanwhile, agree with this or not, we can still do it the good old-fashioned way—and enjoy it.

How to begin? Fitness expert Dr. Charles Kuntzleman makes it look simple: "It's just a matter of choosing an activity and performing it 20-30 minutes, 3-4 days a week."

What activity? For most of us getting along in years or already there, the widely recommended top four are walking, swimming, cycling and jogging. **Any** activity is good—bowling, table tennis, badminton, calisthenics, tennis—but they won't yield the long-run cardiovascular and weight-control gains of the recommended four. At the same time, try to take advantage of everyday-living opportunities for exercise that will help you both achieve and maintain fitness: Walk another 2-3 blocks to the next bus stop — or the next—before boarding; climb the 2-3 flights of stairs instead of taking the elevator; park the car 4-5 blocks from your destination and walk the rest of the way; carry the groceries to the car instead of using the cart.

But before starting your regular exercise program, see your doctor to determine your starting level. Test results will tell you and your doctor what form of exercise is best for you, and how to pace yourself, safely, sensibly, and realistically, from the very beginning.

Try not to expect too much too soon, and keep in mind the long-range and worth-striving-for goal: a new, slimmer, brighter, revitalized you, feeling your best mentally and physically.

It's far from impossible. Wonderful, youthful Lowell Thomas skied cross-country every winter in his 80's; men and women in their 70's are running 26-mile marathons; an 88-year-old lady ran a Virginia Golden Olympics 100-yard dash in 44 seconds, then came back the next year and ran it in 33.

But even if your doctor limits you—to fitness trails, or lawn bowling, shuffleboard, even chair exercises—count your blessings and keep at it.

How about a walk?

Probably no form of exercise can give you so much in return for so little as the simple act of walking.

To start, warm up with a few minutes of slow, low-key walking, then gradually work up to your full stride. You can begin with as little as 10 minutes a day, five minutes out, five back—perhaps a quarter-mile in all. Keep at it, three times a week, on alternate days. For your third week, try making it 10 minutes out, 10 back, lengthening your stride a little.

Back home, cool down with 5-10 minutes of simple bends and stretching exercises.

Walk alone if you prefer, or with a friend or two, or join a walking group, for the fun and companionship. Try wearing wrist-weight bands to build arm and chest muscle tone, muscular endurance and strength. At your own pace, keep extending the distance, gradually upping your speed. Your ultimate goal—it may take 4-6 months or more to reach it: three miles in 45 minutes, 3-4 times a week.

GOOD FOOD, GOOD EXERCISE: KEYS TO GOOD HEALTH

You know you can count on Campbell's for good nutrition. And with **Chunky Soups**, for example, in their individual serving sizes, you enjoy convenience and good taste as well. As the basis of a nutritious lunch or dinner, there's **Old Fashioned Vegetable Beef Soup**, a good source of protein and Vitamin A. Or **New England Clam Chowder**, with Vitamin C and iron.

You also count on Campbell's when you exercise with **Triangle Bands** or use **Triangle Softballs**. They help improve overall fitness and build muscle strength. You'll find **Triangle** equipment at leading sports goods stores.

When You Start Exercising

- Begin your program slowly, especially if you've been inactive. Start with 5-10 minutes twice a week. Add a few minutes each week.
- Before and after exercising, warm up and cool down with a few simple stretching exercises, body bends, etc. Breathe fully as you exercise. Try to keep face and throat muscles relaxed. If arm and chest muscles feel tight, let your arms hang loose and rotate your hands freely.
- Beware of exercising in hot, humid or cold weather. Ask your doctor about sensible temperature ranges for your region, age and condition.
- If you feel distress, such as nausea, chest pains, extreme shortness of breath, joint aches, muscle cramps—slow down or stop. If discomfort persists, check with your doctor.
- To avoid foot ailments and leg problems, treat yourself to the best athletic shoes you can afford, with cushioned soles, strong arch support. Advises Dr. Kuntzleman in **The Exerciser's Handbook**, "Get a good pair of running shoes."

Middle-age/senior fitness: The nutrition imperative

As we age, we need to guard against two tendencies: over-nutrition and under-nutrition. Men tend to the first, women to the second.

Men, as a rule, like to eat too many calories, too much fat, and too much sodium (salt). The first two may lead to serious overweight and a high cholesterol count, both of them threats to good health, to life itself. The third may increase risk of high blood pressure.

Since most women just naturally eat less as they age, they must take care to derive more nutrition from what they do eat. Moreover, female life cycles tend to deplete their systems of vital nutrients, in particular, iron and bone-building calcium. Low iron may lead to the "tired" feelings of chronic fatigue or listless apathy. As for calcium, many women as early as their 30's begin drawing on their reserves. Menopause speeds the process. Risk, later on: osteoporosis or "brittle bones." Good nutrient sources are: for iron — liver, lean meats, whole grains, dark green vegetables, eggs; for calcium — low fat milk products, cheese, dark green vegetables, sardines.

In general, those of us getting older need regular, balanced meals that promote vitality, zest for life, and that fortify us against diseases that shorten it. Here are some simple guidelines:

Try limiting fat intake. To do so, seek all-important proteins from **lean** meat, fish, skinless poultry, legumes. Get complex carbohydrates (for fiber and other essential nutrients) from whole-grain and enriched flour products, beans, brown rice, green vegetables. If you're hypertensive, find a satisfactory sodium-free salt substitute. (Get your doctor's approval.) For dessert, try switching to fresh fruit, angel food cake, gingerbread, ice milk, sherbet.

If you live by yourself, ward off "5 o'clock loneliness" by eating with others as often as possible.

Seven keys to fitness— In spite of the downslope!

Dr. Lester Breslow, dean emeritus of the University of California's School of Public Health, conducted a classic, nine-year study of nearly 7,000 Californians, men and women ages 20 to over 75 who came from varying economic, ethnic and lifestyle backgrounds. The results pointed to one inescapable conclusion: "The daily habits of people have a great deal more to do with what makes them sick and when they die than all the influences of medicine."

Moreover, the study* yielded a concise, sensible program for fitness—seven positive health habits for people of all ages, but particularly those on the "down" side of the life curve. Save them. Study them. Try to blend as many as you can into your life.

1. Usually sleep 7-8 hours.
2. Regularly eat breakfast.
3. Rarely eat between meals (even on a 4-6 meal-a-day regimen).
4. No smoking.
5. Moderate drinking (1-2 drinks a day) or none at all.
6. Good weight control (no more than 10% below or 20% above your desirable weight).
7. Regular exercise.

(In addition, medical and dental check-ups at least once a year.)

"A man (or woman) at age 55 who follows all seven good health habits," says Dr. Breslow, "has the same physical status as a person 25-30 years younger who follows less than three of the health practices."

Those good health habits pay off in a **longer** life as well as a better one. On the average, men and women over 45 who follow six or seven of the good health habits can expect to live seven to 11 years longer than those who follow only three or less.

GOOD AND EASY BREAKFASTS

A good morning meal really matters, because it refuels your energy after your overnight "fast." The easily prepared balanced breakfast here serves as an excellent example. Here's how it contributes to your U.S.R.D.A.—your daily nutritional needs:

■ **Swanson Scrambled Eggs and Sausage with Hashbrown Potatoes** provides 20% of the protein and riboflavin and 15% of the thiamine and iron. **Pepperidge Farm Raisin Bread** (2 slices) supplies carbohydrates. Six ounces of **"V-8" Vegetable Juice**, with only 35 calories, gives you 45% of the Vitamins A and C you need daily.

■ For more fiber, enjoy **Pepperidge Farm Cracked Wheat or Whole Wheat bread.**

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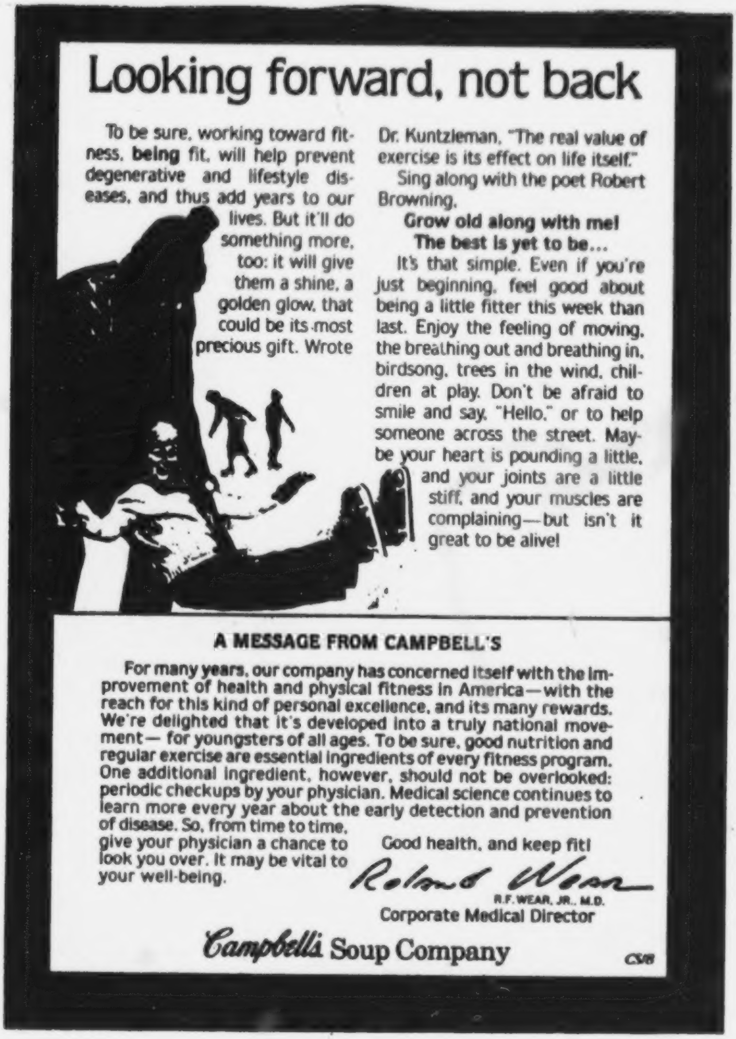
*Belloc, Nedra B. and Lester Breslow, "Relationship of Physical Health Status and Health Practices," Preventive Medicine, Volume 1, No. 3, August 1972

Definition of the over-60 years:

"The Metallic Age: gold in your teeth, silver in your hair, and lead in your pants."
(from a national symposium on fitness and aging)



Looking forward, not back

To be sure, working toward fitness, **being** fit, will help prevent degenerative and lifestyle diseases, and thus add years to our lives. But it'll do something more, too: it will give them a shine, a golden glow, that could be its most precious gift. Wrote Dr. Kuntzleman, "The real value of exercise is its effect on life itself."

Sing along with the poet Robert Browning,

Grow old along with me!
The best is yet to be...

It's that simple. Even if you're just beginning, feel good about being a little fitter this week than last. Enjoy the feeling of moving, the breathing out and breathing in, birdsong, trees in the wind, children at play. Don't be afraid to smile and say, "Hello," or to help someone across the street. Maybe your heart is pounding a little, and your joints are a little stiff, and your muscles are complaining—but isn't it great to be alive!

A MESSAGE FROM CAMPBELL'S

For many years, our company has concerned itself with the improvement of health and physical fitness in America—with the reach for this kind of personal excellence, and its many rewards. We're delighted that it's developed into a truly national movement— for youngsters of all ages. To be sure, good nutrition and regular exercise are essential ingredients of every fitness program. One additional ingredient, however, should not be overlooked: periodic checkups by your physician. Medical science continues to learn more every year about the early detection and prevention of disease. So, from time to time, give your physician a chance to look you over. It may be vital to your well-being.

Good health, and keep fit!

Roland Wear
R.F. WEAR, JR., M.D.
Corporate Medical Director

Campbell's Soup Company

CSW

Mr. WYDEN. Thank you both, and really for a first rate job.

Let me start with you, Dr. Feder. You talk about the clear and important role for the Federal Government to play in providing long-term care. If we say that the Medicare and the Medicaid Programs would be the appropriate mechanisms to do it, what kinds of changes would you suggest be made to Medicare so that seniors do have access to long-term care services?

We would be interested in your perceptions. As you know, there are people who advocate a part C, people who advocate modest additions, medium-sized additions. We would be interested in your thoughts with respect to changes on Medicare.

Ms. FEDER. If one advocates insurance for long-term care, the best insurance program is one that spreads the risk among the greatest population possible. It is hard to argue against a social insurance program, tax financed, as the ideal approach.

One cannot, however, ignore that there are budget pressures that make that quite difficult, if not impossible, in the short term. It doesn't mean we shouldn't keep it in mind as a goal and one could begin to tax now for such a program far in the future.

However, put the ideal aside for the moment and look at the current situation. I think one of the areas that Medicare should pay most attention to at the moment is in improving its short-term/long-term care coverage. As I said, I think Medicare has exacerbated the problems of obtaining long-term care and nursing home care with the hospital prospective payment system. I think it is quite important that Medicare look at its nursing home and home health coverage, see that it is adequately available, examine the prospective payment system, adjust the outlier policy if that is creating a problem to keeping patients in hospitals and address that problem in the short term.

Mr. WYDEN. The administration has said on a number of occasions that States receive enough Federal Medicaid dollars to care for the elderly poor, and that, in effect, inefficiencies are the reasons why poor older people aren't getting the needed services at the State level.

We would be interested in your appraisal. Are the States mismanaging their resources or are there just not enough resources to go around to meet the great need?

Ms. FEDER. States probably are not paragons of efficiency, but I think that they have demonstrated enormous innovation as well as restrictiveness in the administration of their long-term care programs. Many States have constrained their nursing home payment systems, innovating in the area of in-home care and making great efforts to do that in an efficient manner.

They are also restricting what they spend in perhaps less desirable ways, simply setting limits on the bed supply as I mentioned earlier. The sum total of their efforts means that the resources going into this area are limited, and I think it would be a mistake to assume, given the needs that we have discussed in the population, that one could finance sufficient care through more efficient services.

Mr. WYDEN. My colleague is on a very tight schedule, and I want to yield to him whatever time that he would like to pursue questions. Then I will have some more.

Mr. **Bilirakis**. Thank you, Mr. Chairman.

You are considerate. I appreciate that. I would like to just continue on your point if I may.

We talk in terms of expanding Medicare services for long-term care. Should we do that merely by mandating expansion, knowing that it is going to tax the system that much more? Should we do that by mandating expansion, but probably tying in some of the other concepts that I have heard, such as some premium payment on the part of the elderly person, whether it be on the part of the elderly person or whether it be at a time before they reach that particular point.

Ms. **Feder**. As I said earlier, I would argue for ultimately mandating such a program, but I think that you are quite right to focus on what contributions people can make and structuring those contributions thoughtfully.

I think that premium financing, although I don't think the program could be solely premium financed——

Mr. **Bilirakis**. Why not?

Ms. **Feder**. I think the costs exceed what we would be able to obtain from the elderly population in affordable premiums.

Mr. **Bilirakis**. Could you sell it to the premium payer?

Ms. **Feder**. To—you mean sell it to those who would buy?

Mr. **Bilirakis**. Yes.

Ms. **Feder**. I think that a voluntary program, whether in the public or private sector, runs the risk of adverse selection. We don't know who will buy and who won't. The concern is that the people who most need the services will be the ones who buy and that affordable premiums will be insufficient to cover the cost of those needing the service.

I think it is appropriate to require premiums but I am not sure that a program that is offered on a voluntary basis would be effective.

I also think that we could build up a fund in advance. I think it might have to be taxes if we were building it in advance, but if we were to tax the younger population today and build a fund for the future——

Mr. **Bilirakis**. There would be a revolution.

Ms. **Feder**. Let me add, we were focusing on the premiums. That is not the only area. I think a program need not be first dollar, totally comprehensive. One can require cost-sharing contributions, could design a catastrophic, long-term care program and take in substantial resources from people in that way, not simply on the premium side.

Mr. **Bilirakis**. Ms. Louden, you have mentioned that in the stages of getting older, the 85 and older, their income decreases. Why is that? Why does it increase, if you will, at 65 and 75 and decrease at 85?

Ms. **Louden**. There are a couple of reasons.

First, if you are looking at depletion of assets as they get older, in the young-old years, they can take some of that pension and they can take some of their assets that they have saved and use that to spend. As they get older, they don't have that availability and they have spent a lot more on health care as they have gotten older, and therefore their spendable income is greatly reduced.

They also in many cases have, particularly for women, are alone at that point. Women in particular do not have some of the pension coverage and funding. I might add something else, even if women working and they think that is going to be helpful. If you look at the way the pension funds are set up today, you have to work 10 years to vest. Women don't work 10 years in a row, and even men don't anymore, and that is going to be a very interesting impact on the pension funding in this country, because people don't stay with one company like they used to.

Women tend to work in small businesses, in retail. These places do not provide pensions. So I don't care if you have worked your whole life on and off and if you have worked as a small business, small businesses employ everybody but the Government wants employment, but they cannot afford and you ought to look at HMO coverage for small businesses, too. It is not there.

When you start looking at 85 and over, that is who you are looking at.

Mr. **Bilirakis**. I thought that would be your answer, but I wanted to get it on the record.

I am going to have to leave. I would merely ask both of you if you would do what your predecessors have done as witnesses, and I would appreciate you submitting for the record, any suggested concepts/ideals you may have becausewe have to address this overall problem and put our citizens first.

Mr. Chairman, we aren't talking here about a case where there may be alternatives for people. If you need medical care, you need medical care, it is that simple, and this is a conservative Republican talking.

You will forgive me, Mr. Chairman and witnesses, but I have to catch a plane. I don't have alternatives because it is not a private plane. It is not a junket, either. But in any case, I appreciate your taking the time to appear here.

Mr. **Wyden**. We thank the gentleman for his interest, and certainly look forward to working with him in the days ahead. Dr. Feder, just a couple of other questions for you and Ms. Louden. Obviously, there are a variety of financial alternatives that we are going to look at to try to grapple with the comprehensive program. But I think one of the things that our subcommittee clearly feels is essential is to decide what population group we want to cover, who we ought to worry about first, and what kinds of services are most appropriate. Maybe you could shed some light on that.

Ms. **Feder**. I think there is no question when we have limited resources and we have to choose, that we have to focus on the people who have the least resources to fend for themselves, the poor and the near poor. I think in that regard, while we focused heavily on expanding Medicare, we may not be able to do that in the short term, and we therefore ought to look to improving our last resort program, the Medicaid Program.

When it comes to services, I think we need to give attention to the in-home and community-based care and to the nursing home side, which we sometimes forget. To meet needs for in-home care, we would ideally expand the 2176 Waiver Program, perhaps, to make it an optional benefit, certainly to reduce some of those constraints that are currently imposed on waivers for nursing homes as well as in-home care.

I think that we might also look at the Medicaid matching formula or other mechanisms to put greater Federal resources into the States that have the greatest needs for long-term care, the largest elderly populations. I think that the Federal Government might take a greater role in overseeing State programs, identifying States who are innovating in the design of their long-term care programs, and perhaps either encouraging or requiring that some of those innovative mechanisms be used in States that have not been so adventurous.

Mr. **WYDEN**. Good suggestions. Let me turn to the private sector from you, Dr. Feder, and we will slide into some questions of you, Ms. Louden. If you had to make some appraisals today, Dr. Feder, how many older people could afford private long-term care insurance? Is it 5 percent, 10 percent? Could you give a rough guess at how many could?

Ms. **FEDER**. I think that the concept of affordability is a difficult one to address, because we are talking about a price for an insurance package, and I am not sure that a package properly designed to provide the benefits that we would like to see people have would be affordable by very many. So I would not venture a guess at a number.

I think that the elderly themselves, when surveyed, have not expressed a willingness to pay as high rates, roughly $500, as people have estimated that a package would cost, and I think those estimates are low.

Mr. **WYDEN**. $500 annually?

Ms. **FEDER**. But, as I say, I think those estimates are low. I don't know what those packages provide, and the pricing of those packages is theoretical. They have not taken into account extra use that is likely to come if a service is insured, so I think it is on the low side and it is not clear that the elderly are willing to buy it.

Mr. **WYDEN**. Ms. Louden, your answer to that same question?

Ms. **LOUDEN**. I disagree. I think you underestimate the power of the consumer marketing companies and the insurance companies. I have an article here actually from Business Week magazine. It says, "Today only about 100,000 or fewer Americans have long-term health care insurance to cover nursing home bills, but that is about to change with the number of big private insurance firms moving into the market. Aetna, Metropolitan Life, AIG, and Prudential will start offering long-term care insurance this summer and fall. Entering the market, they estimate, will total $3 to $5 billion within 5 years. Blue Cross-Blue Shield is considering the move." And it goes on.

Mr. **WYDEN**. Without objection, we will make that Business Week article a part of the record as well. I read that and it was probably the most detailed account I have seen up to this point. [See p. 99.]

Ms. **LOUDEN**. Yes; it was an excellent article. I think what it says, and I guess my feeling would be, that upwards of 50 or more percent of the total elderly population, including their children, who will also help pay, could afford this and they would pay. The reason they would do it over time is because they will be educated. They will be educated by these insurance companies of what it means to them if they don't and that is the whole concept of asset protection. What does it mean to you if your parents have to go into a nursing home.

Mr. **Wyden**. You think 50 percent today of seniors and their families can afford private long-term care?

Ms. **Louden**. No; I am saying the potential market.

Mr. **Wyden**. Oh, potential.

Ms. **Louden**. With education. I am just looking at what happened with all the other kinds of insurance. Look at how many have wraparound coverage right now, Medigap coverage. A very significant portion have Medigap.

They pay for that, and I think there is a revolution going on in this country, and that is that people are understanding health care more than they ever did and they are more concerned, so I guess my feeling is that over time—and I go back to segmentation—there will be a significant portion that would be able to afford this, and that would be interested enough because of the protection issue. I think there is a significant issue related to the segments that will not be able to afford it, and that is where I think there has to be public policy.

Mr. **Wyden**. Dr. Feder.

Ms. **Feder**. I think two points need to be made in this regard. First of all is what elderly people believe about the likelihood of their needing nursing home care. I think in this area, surveys indicate that most do not believe that they are going to need long-term nursing home stays, and they are right. Very few people ultimately have long stays in a nursing home, and it is not at all clear that it is a wise investment on their part to pay high premiums for many years for a service they will never require.

The second point is that it is absolutely clear that insurance companies and other entities are interested in the elderly market, but I think we have to look very closely at what they are offering, and they are quite explicit about this. They are very cautious, and they protect themselves in a number of ways, as I think your legislation recognizes. As a result the benefits that they provide are not the benefits that we are talking about as necessaryto truly protect peopleagainst catastrophe. So while many people may buy policies, they may still be exposed to financial catastrophe.

Mr. **Wyden**. I am not sure the two of you disagree all that much.

Ms. **Feder**. I think that is right.

Ms. **Louden**. Yes.

Mr. **Wyden**. This is very much uncharted ground. I have been one of the big champions of the private insurance concept up here, and I am the first to say this isn't going to meet all the needs. I would be ecstatic if they could meet 10 percent of the needs of older people. It seems to me by way of what Dr. Davis and I talked about that 10 percent that can be met by the private sector possibly frees up 10 percent of the resources so that we can help low-income people.

I think that this is by no means just rosy, how do we reach for the gold kind of business. We are very concerned on this subcommittee about the dangers of fraud, and have gone to considerable lengths in our modest approach in the reconciliation package to have marketing protections and other kinds of information, just by way of voluntary guidelines.

This is very much uncharted ground, and both of you have really said we are going to need a significant public kind of program that is going to cost some money to handle low-income people. For these people there is no great market—companies tripping over themselves to get at those older people and their families. And then the question is, can we possibly get those people who can afford it private long-term care insurance with decent protections?

Ms. **Feder**. Right.

Mr. **Wyden**. Can we get policies that companies can profit off of and sell the American people?

Ms. **Louden**. Can I add one thing?

Mr. **Wyden**. Yes, please.

Ms. **Louden**. I think that one of the issues going to home-care insurance, it might be something that the Government might want to think about, is that most long-term and care insurance is heavily oriented toward nursing home care, because that is the thing most people are concerned about, if they had to go into it. The 85 and over, 22 percent, almost one-quarter of the 85 and over, is in a nursing home. It is a much higher percentage. It is not your sixty-fives. It is your over eighty-fives, so there is a significantly high percentage at that age. But I think the issue of home health care and for families, the coverage that would be provided through home health care, is something that is going to be interesting to watch and to be tested—and all of this is a test; it is going to be interesting to see some of the data that comes out.

I would encourage the Government to make sure that as these insurance companies get into this, that that information that they are gathering is collected, and I know how hard it is to get, because they are not going to want to share it with all their competitors, but I think it is important that we have some information data on it, because you are right. We just don't know.

Mr. **Wyden**. That is another reason for the approach, it seems to me that we take in our bill. Given the fact that there isn't much information, we will have the best minds from the National Association of Insurance Commissioners and the senior advocacy groups and the private companies, all trying to work through these issues. Presumably there will be some information sharing as a result of it. I think that is one of the attractive things that we ought to be doing on the plane of legislation.

A couple of other questions about private long-term care, Ms. Louden. We are interested in the relationship between DRGs and what is happening with the private sector long-term care market. Of course, you have heard, I know, about the debate over whether people are being discharged more quickly, when they are still fairly sick. Has the private sector long-term care market responded to DRGs?

Ms. **Louden**. I think the private sector has very much responded to DRGs, particularly if you look at the growth in investment and building of private nursing homes, the money going into what I call nursing homes for the rich. I have some friends that have actually started those and are calling them things like Whitehall. There are some very interesting names and things that are going on in that area.

Mr. WYDEN. Called what?

Ms. LOUDEN. The Whitehall, just like the Whitehall Hotel in Chicago. It is a very ritzy hotel. They don't call them nursing homes. They give them names. You have seen these.

Ms. FEDER. Yes.

Ms. LOUDEN. That has only been in the last few years. You have seen a lot of money poured into that. Home health care, private duty nursing has expanded dramatically in this country.

Mr. WYDEN. Again, in your view because of DRGs?

Ms. LOUDEN. Very much so. I mean, just home care in general, the visits are up dramatically, and a big part of that is not just individuals going into nursing homes. The nursing homes are at 99-percent occupancy. You have got to put them somewhere. For that reason home health care has expanded.

Our hospitals in the last 2 years, three-quarters of our business requests are how do we get into home care, and they don't want just Medicare agencies, by the way. They are looking at the private side of that. They are looking at private duty nursing. They are looking at durable medical equipment, because they can't afford to just have a Medicare agency. But yet I would say that the private sector has very much responded, because of the increased demand brought about by the Medicare prospective payment.

Mr. WYDEN. You mentioned in your testimony that DRGs have forced even some of the not-for-profit organizations to get involved in for-profit long-term care activities. Could you tell us a little bit more about this, and how it works?

Ms. LOUDEN. Sure. If you look at, for example, hospitals, they are getting into not only the public nursing home, your typical nursing home. They are looking at private nursing homes. We have hospitals that are acquiring warehouses and turning them into adult housing, and there is adult day care centers that they are looking at, that they are combining with child day care centers for intergenerational programs.

There is the private duty nursing that they are getting into. There is pre-retirement planning programs, sports fitness for the elderly, osteoporosis, pain clinics. I can list a hundred of them. We have a program, a seminar actually, that we are running for the first time. It is called hospital sales. It is how they can sell all those programs, because that is what they are doing. They are at 50-percent occupancy. All of those programs are a response. They are also, hopefully, a way to make revenue to offset what they have lost.

Mr. WYDEN. As you know, our subcommittee has been very supportive of the waiver concept, specifically the 2176 waivers, more availability of home and community-based kinds of services. Do you think the private sector is willing to play a role in offering these kinds of services to the Medicaid population?

Ms. LOUDEN. If you give attractive reimbursement, I am sure they will be happy to look at it. I can tell you what has happened in the home health care market. As you may know, the Medicare home care reimbursement has been capped and changed dramatically in the past year, as has the durable medical equipment reimbursement. Not too long ago, Beverly Enterprises, the largest nursing home chain in the country, pulled out of the Medicare home health care business. They had about 90 of their agencies they closed. They are now targeting only private duty home health care. The same thing with Kelly, which is a national provider of home health care. They dropped their Medicare agencies, and the reason for that is the reimbursement was so bad they just said, "Forget it, we are going after private dollars." And so I would say, yes; the private sector is more than willing to listen, but if the reimbursement is there to provide a return.

Mr. **Wyden**. What level of impairment is the private sector willing to treat? This is really the question. We all hope that there will be higher reimbursements. This subcommittee has worked very hard under Chairman Waxman's leadership to do that. But as of now, what level of impairments is the private sector willing to treat? Is this it? Is this the maximum, what is out there today?

Ms. **Louden**. I think that the private sector does not really look at it from an impairment basis. They look at it from a dollar basis.

Mr. **Wyden**. Clearly if there are impairments, and your low-income face serious kinds of problems, those two are intertwined, aren't they?

Ms. **Louden**. That is exactly right, and that is what I am saying. No matter what your impairment is, if there isn't the ability to generate revenue from that base of population, then it is not attractive. It doesn't really matter what the impairment is so much as looking specifically as is there reimbursement.

I will give you an example. Home ventilator patients, dramatic market increase in that market, and what we are looking at is a situation where a lot of private insurers have suddenly added that, and all of a sudden every respirator home care company in the business is coming in saying, "Teri, I want to be in the home ventilator business." So it is that whole idea. Those are chronic patients. They certainly are disabled. They will be on that ventilator, many of them, the rest of their lives. But they become attractive if someone pays for their care. That is, I guess, the only way I can really answer that.

Mr. **Wyden**. A question for both of you. The administration, as you know, is very much in favor of the idea of the voucher concept in terms of providing access to health care and long-term care services. Of a wide variety of different approaches, they think that vouchers would be the way to go. Under this kind of approach older people would basically, under their theory, have the chance to purchase a set of health services that would best fit their needs. Do you think a voucher idea works for long-term care services? I would ask each of you, Dr. Feder and Ms. Louden.

Ms. **Feder**. I think that I would simply pick up on what Ms. Louden has just well expressed, and that is it depends quite heavily on the size of the voucher. I think that the notion of a voucher, because it allows freedom of choice and more flexibility, whatever, being able to save tremendous amounts of money over what we currently spend, is not a very well-founded notion, and I am also concerned that if prices are set for vouchers, that they are easily lowered over time or not raised to keep pace with the cost of services, so that my view is that it is an area to be concerned about, not to promote simply for ideological reasons.

Mr. **Wyden**. Ms. Louden.

Ms. **Louden**. I have two points to make regarding that. The first would be that I don't think that the older adult population is educated enough to be able to use a voucher. If you are goign to produce a voucher for long-term care, then you are going to have to put massive dollars into education, and I don't think you are willing to do that.

I think the second thing—going back to Dr. Rowe. Give the voucher to the physician, and educate them and give them a cap and let them be involved in this. Part of the reason they are not interested in this market, because there hasn't been Medicare HMOs. They certainly became interested in general HMOs as they started losing visits and dollars, became much more interested in preventive health.

I think that if there is an emphasis in that direction, of getting them to help coordinate and be part of that coordination, that it is going to be a lot better than giving that to the individual who really can't make the decision.

Mr. **Wyden**. I don't have any further questions. I think you two have really provided us with a very helpful panel. We might have had someone who thinks that we just ought to have taxpayer-financed programs and let's just go with that, and another panelist who said let's just have private programs, and let's just go with that.

But as I listened to the two of you, I see there were clearly foundations for interactions between the two approaches and a chance to use both of them to try to meet needs in this area. We thank you both for your participation. Unless you have any further comments, we will excuse you.

Ms. **Louden**. Thank you.

Ms. **Feder**. Thank you.

[The following letter was submitted for the record:]

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Georgetown University
School of Medicine

Department of Community
and Family Medicine

November 6, 1985

Congressman Henry Waxman
Chairman
Subcommittee on Health and Environment
Committee on Energy and Commerce
512 Annex 1
300 New Jersey Avenue, S.E.
Washington, D.C. 20515

Dear Congressman Waxman:

Thank you for the opportunity to appear before your committee. As Congressman Bilirakis requested, I am submitting my views on the best way Congress could address problems in long-term care.

During the hearing it was suggested that the private sector will handle certain segments of the elderly market--the profitable segments--and that government should take care of the rest. Although private insurance might protect some of the better off, it is my belief that distributing responsibility between the private and public sectors in this way would be decidedly inefficient.

To the extent that private insurers offer long-term care insurance, they target their marketing to the healthy, wealthy elderly, few of whom will actually use benefits. Furthermore, they define benefits in ways that limit their risk as well as the protection purchasers receive. Hence insurers may earn substantial revenues and pay out very little. Although regulation might address this problem--by mandating benefits and requiring minimum loss ratios--such regulation is costly and not always effective. Even if it were effective, high marketing costs and consumer difficulty in evaluating policies would remain. Furthermore a perception, however misguided, that private insurance is doing the job, may make it more difficult politically to tax the better off sufficiently to finance care for people unable to buy insurance.

My recommendation to Congress is to recognize that private insurance will do no better a job in financing long-term care than it did in financing acute care for the elderly before Medicare. What is needed is a Medicare benefit to protect against catastrophic long-term care expenses. Catastrophic expenses could be defined in dollar terms (e.g., expenses above $5,000) or as a percent of income (e.g., expenses in excess of 10 percent of income). A benefit designed as catastrophic provides protection without eliminating patient responsibility for payment.

To spread the cost of such a benefit across the largest possible population, financing would ideally be through payroll taxes or general revenues. To alleviate concern about unpredictable costs, taxation could begin in advance (by perhaps ten years) of the benefit's introduction, allowing the government to build up a fund to protect against the financial uncertainties of long-term care insurance.

Alternatively, the program could be financed through premiums paid by the elderly. These premiums should be added to Part B, not separate, to assure maximum participation of the elderly population. Such premiums should be modest, since the benefit would require the elderly to pay substantial amounts out-of-pocket. Therefore, premiums should be subsidized if necessary.

Until such a position is enacted, improvements in Medicare's coverage of short-term post-hospital care and Medicaid enhancements could alleviate problems faced by current elderly. Medicaid enhancements could include better protection of spouses' or other dependents' resources, fewer restrictions on coverage of in-home and community based care, alteration of the matching formula to provide more funds to states with high proportions of elderly, and greater federal oversight of state policies to assure efficient methods of paying providers and controlling utilization.

I congratulate you and your subcommittee on this effort to improve long-term care financing and am glad to be of assistance.

Very truly yours,

Judith Feder

Judith Feder, Ph.D.
Co-Director

Mr. **Wyden**. We are going to take a 5-minute break before the start of panel 3. We will resume in 5 minutes.

[Brief recess.]

Mr. **Wyden**. The subcommittee will come to order. Our last panel today comprises representatives of various long-term care delivery systems that are now available in the United States. Mr. Jack Ebeler is vice president of Group Health, Inc., based in Minneapolis. Group Health is the site of one of four Medicare HMO demonstration projects.

Mr. Lloyd Lewis operates a life care community program private sector delivery system that has grown tremendously in the last few years. That program is located outside Philadelphia.

Marie-Louise Ansak, from On Lok, a senior health program to assist the frail and elderly in San Francisco. That program is being financed in part through Medicare and Medicaid programs.

Mr. **Wyden**. We thank all of you for coming, a chance to see some familiar faces. We will make copies of your prepared remarks a part of our record in their entirety, and if you could summarize some of your key concerns, we will have plenty of time for questions. We have a number for all of you.

So let us begin with you, Mr. Ebeler. Welcome.

STATEMENTS OF JACK EBELER, VICE PRESIDENT, CORPORATE SERVICES, GROUP HEALTH, INC.; LLOYD W. LEWIS, EXECUTIVE DIRECTOR, KENDAL-CROSSLANDS; AND MARIE-LOUISE ANSAK, EXECUTIVE DIRECTOR, ON LOK SENIOR HEALTH SERVICES

Mr. **Ebeler**. Thank you, Mr. Wyden. Having had the privilege of working on the staff 3 years ago, I know first hand of the subcommittee's commitment to addressing long-term care issues. I am pleased to have this chance to work with you again in that effort.

Our panel is reviewing delivering system alternatives. I have been asked to review one such alternative, the social HMO [SHMO]. Group Health, Inc. and the Ebenezer Society in the Twin Cities jointly developed our social HMO, called Seniors Plus. It is one of four sites where this concept is being tested nationally by the Health Care Financing Administration, including the Kaiser-Portland plan that you mentioned in your opening statement, Mr. Wyden.

I want to present four items for the subcommittee's consideration this morning:

An overview of current problems in delivery and financing of long-term care services;

A summary of the social HMO model;

Some specific examples of how Seniors Plus cares for the elderly today; and

Finally, some idea of what you can expect to learn from the social HMO demonstration as you pursue the development of long-term care policy.

The problems were covered by a number of your witnesses earlier this morning and by the excellent CRS paper that was prepared for the subcommittee. Let me summarize summarize those problems:

First in the area of financing, our public and private financing systems are biased towards acute care and institutional care. They simply do not cover the spectrum of long-term needs of the elderly.

Second, the problems in delivery stem from the fact that we do not offer an integrated system of care. Needed long-term care services are often not available because they are not covered. In addition, the delivery of acute services remains artificially fragmented from the delivery of long-term care services. As a result, services are fragmented for the population that most requires a continuum of care to meet their needs.

Third, the full spectrum of services that an elderly person needs is not coordinated. Instead, we leave it to each elderly consumer, their family, and friends, to negotiate their way through a complex system at the very time they are least prepared to do that—when they are ill.

Finally, the cost of long-term care services continues to rise. Medicaid picks up the major portion of catastrophic long-term care costs, and the elderly generally have to impoverish themselves to get that coverage. While we are beginning to address the problem of acute care costs, we have not yet addressed long-term care costs.

The social HMO model applies many of the proven concepts of HMOs to the long-term care field. HMOs like group health have been shown to provide quality care that is as good or better than the fee-for-service system at a more affordable price. The social HMO is a prepaid, managed system of health and long-term care designed specifically to meet the needs of an elderly population.

The social HMO finances and delivers a full range of comprehensive hospital, medical, and long-term care services. While there are limits on the annual and lifetime amounts of long-term care, due to the uncertainty of insuring those benefits, it remains quite simply the most comprehensive coverage available.

The social HMO integrates this delivery system and coordinates the care needed. The core is a case management system, a unit of nurses and social workers. They work with the client, the family, and the providers to identify and arrange for the care needed.

Finally, as a prepaid entity, the social HMO offers an alternative to the backward incentives in traditional financing and delivery programs. The elderly pay a limited amount of out of pocket—just $29.50 per month in our Seniors Plus plan and the social HMO is at risk to provide services in a cost-effective manner, with risk sharing by Medicare during the demonstration phase.

Currently, more than 5,000 elderly persons are enrolled in the four national sites, including 372 in Seniors Plus in Minneapolis.

Those statistics tell just part of the story. The potential impact of this approach can be seen more clearly if we look at some specific case studies. Let me briefly review one to give you a sense of the human side of the program. An elderly couple in their seventies are members of our plan. The woman has Alzheimer's and is cared for at home by her husband. Seniors Plus provided adult day care services 3 days per week to provide some relief to her husband and to keep her involved in the community.

When the husband needed to go to the hospital for major surgery, Seniors Plus covered her nursing home services while he was in the hospital. Upon his return, she was also returned home, but with an expanded day center service package, and with homemaker services to help them out during his period of recovery from the surgery. He is now recovered, and her day center services are once again back to three times per week. He attends a care-giver support group to give him some experience in learning how to care for the disabled, and some support among people who are in similar situations as himself.

Some other case studies have been included with the testimony, Mr. Wyden.

We are excited about the concept, but it remains a demonstration. The issue for the subcommittee, and for all those involved in public policy, is what can you expect to learn from that demonstration. The following are some of the questions that we hope we will be able to answer for you in the future as you develop long-term care policy.

First, are access and continuity of care actually improved through case management?

Second, will expanded long-term care benefits actually cause the elderly to enroll in a plan?

Third, is quality comparable in a social HMO setting? Quality has been proven to be as good or better in traditional HMOs, but can we expect that for long-term care for the elderly?

Fourth, will the increased availability and use of outpatient and community services actually result in lower inpatient utilization, both in hospitals and in nursing homes?

Finally, will the cost for Medicare, for Medicaid, for the Social HMO itself and for the elderly beneficiary be reduced?

The demonstration provides an opportunity for all of us tolearn about these issues at the same time we serve the elderly. Those of us involved are grateful for this subcommittee's continued leadership and look forward to continuing to work with you. Thank you.

Mr. WYDEN. We thank you for your usual excellent job, Mr. Ebeler, and we will have some questions in just a moment.

[Testimony resumes on p. 137.]

[The prepared statement of Mr. Ebeler follows:]

GROUP
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STATEMENT ON SENIORS PLUS

A SOCIAL HMO SPONSORED BY GROUP HEALTH, INC.

AND THE EBENEZER SOCIETY

PRESENTED TO THE SUBCOMMITTEE ON HEALTH & THE ENVIRONMENT

BY

JACK EBELER

VICE PRESIDENT, CORPORATE SERVICES

GROUP HEALTH, INC.

2829 UNIVERSITY AVENUE S.E.

MINNEAPOLIS, MINNESOTA 55414

OCTOBER 18, 1985

AN EQUAL OPPORTUNITY EMPLOYER

Mr. Chairman, it is a pleasure to be here this morning as the Subcommittee reviews long-term care issues. Having had the priviledge of working on the Subcommittee staff three years ago, I know first-hand of your commitment to enhancing our knowledge of the complex long-term care problems confronting us, and to developing appropriate public policies to resolve those problems. I am pleased to have this opportunity to work with you again in that effort.

Our panel this morning is reviewing delivery system alternatives, and I have been asked to review one such alternative -- the Social HMO (SHMO). Group Health, Inc. and the Ebenezer Society in the Twin Cities developed our Social HMO, called Seniors Plus, as one of the four sites where this concept is being tested nationally by the Health Care Financing Administration. The other three sites are Elderplan in Brooklyn, New York; SCAN Health Plan in Long Beach, California; and Kaiser-Portland, in Portland, Oregon.

I would like to present four items for the Subcommittee's consideration this morning:

- An overview of current problems in delivery and financing of long-term care services;
- A summary of the Social HMO model;
- Some specific examples of how Seniors Plus cares for the elderly today; and
- Finally, some ideas of what you can expect to learn from the Social HMO demonstration as you pursue the development of long-term care policy.

Current Problems

The problems in delivery and financing long-term care services have been reviewed before by this Subcommittee and were covered by a number of your witnesses earlier this morning. Let me summarize some of the problems that Social HMOs like Senior Plus are trying to address.

- **Financing:** Our public and private financing systems have created problems because they are biased toward acute care and institutional care. They usually do not cover the spectrum of long-term needs, especially non-institutional needs, of the elderly.

- **Delivery System:** The problems in the current delivery of services stem from the fact that we do not usually offer an integrated system of care.

  -- Needed long-term care services, especially home based and non-institutional services, are often not available to elderly citizens because they are not covered by insurance.

  -- The delivery of acute medical services remains artificially separated from the delivery of long-term care services. Services are fragmented for a population that requires a continuum of care to meet their needs.

- **Coordination:** The full spectrum of financing and delivery services that an elderly person needs is not coordinated, because we have not integrated the financing or the delivery system in a logical way. As a result, we leave it to each elderly consumer and their family and friends to figure out and negotiate their way through a complex system at a time when they are least prepared -- when they are ill.

- Cost: The cost of long-term care services continues to rise, with Medicaid picking up a major portion of catastrophic long-term care costs once the elderly have impoverished themselves. For example, in Minnesota, we have succeeded in bringing acute care costs per capita to 10.1% below the national average by moving toward more competitive pressures on providers through HMOs. However, no such competitive pressures exist in long-term care, and our long-term care costs are more than double the national average.

The Social HMO Model

The Social HMO model applies many of the proven concepts of HMOs to the long-term care field. The Social HMO is a prepaid, managed system of health and long-term care designed to meet the needs of an elderly client population. The key features are as follows:

- Financing and Delivery. The Social HMO finances and delivers a full range of comprehensive hospital and medical services, and long-term care services, including in-home and non-institutional services such as homemaker services, care-giver education and support, and respite services. It is quite simply the most comprehensive coverage available, and a complete summary of the Seniors Plus benefit package compared with Medicare coverage is attached for the record.

- Coordination. In addition to financing and delivering the full range of services, the Social HMO integrates this system and coordinates the care needed by the individual. The core of the system is a case management unit of nurses and social workers who work with the client, family and providers to identify and arrange for the care needed to meet the individual needs of the elderly.

- Costs. As a prepaid entity, the Social HMO and its providers offer an alternative to the backwards incentives in traditional financing and delivery programs. The elderly pay a limited out-of-pocket premium -- just $29.50 per month in Seniors Plus -- and the Social HMO is at risk to provide services in a cost effective manner. Since a full range of services is available, the case manager and provider can select the most appropriate care for the individual, and not default to expensive hospital or other institutional care because it is the only option.

Current Situation and Case Examples

Currently, more than 5,000 elderly persons are enrolled in the four national sites, including 372 in Seniors Plus in Minneapolis.

The statistics tell just part of the story. The potential impact of this approach for the elderly can be seen more clearly if we review some specific case studies from Seniors Plus. Copies of three such case studies are attached, but let me briefly review them for you.

- The first is an elderly couple in their 70's. The woman has Alzheimers, and is cared for by her husband. Seniors Plus provided adult day care services 3 days per week to provide some relief to her husband and to keep her involved in the community. When the gentleman needed to go to the hospital for major surgery, Seniors Plus provided nursing home services for her. Upon his return, she was also returned home, with daily adult day center services, and homemaker services during his recovery from the surgery. He is now recovered, and her day center services have been scaled back to 3 times per week. In addition, he has attended a care giver support group offered by Seniors Plus to learn more about caring for the disabled and for himself.

- The second is a 70 year old woman with a number of health problems, and difficulties with daily activities. However, she is determined to stay at home as long as she can.

  She receives daily homemaker and health aide service from Seniors Plus, and a Lifeline Emergency Response System so she can call for help if she has a fall or cannot reach a telephone. She receives home delivered meals for her main hot meal of the day. She attends day center twice a week, and a nurse at the day center monitors her health conditions. She also sees her physician on a regular basis for regulation of her medications.

She would need nursing home care if she did not have Seniors Plus services available to her. Her income is limited and if she entered a nursing home, she would be on Medical Assistance within 90 days. The total cost of care is now approximately $995/month. If she were in a nursing home on Medical Assistance, the average area monthly cost would be $1,478.

- The third case is an 88 year old widow, living in a senior high rise, with mild memory loss and confusion. At the time she enrolled in Seniors Plus, she was doing her own housework and personal care.

Soon after her enrollment, she was taken to the Emergency Room due to complaints of severe back pain and sudden inability to walk. She was admitted to a transitional care SNF facility in lieu of hospitalization, which would have been the only reasonable alternative in this case. Her mental confusion increased, so she was transferred to an intermediate care facility to attempt to stabilize both her physical and mental health.

Her wish was to return to her apartment, and her physician supported that goal. As she improved, a physical therapist took her to her apartment to evaluate her ability to function safely. A home care plan that included homemaker/health aide service and maintenance home physical therapy treatments was established through her case manager.

She is now home. She still shows mild signs of mental confusion and poor judgement. For example, she recently purchased $2000 in hearing aids from a door-to-door salesman without realizing she has coverage for that service under Seniors Plus. The case manager was able to work through Legal Aid to get the contract cancelled.

Her ability to remain at home is fragile and depends largely on her mental status. Her home care plan has now been able to be reduced to homemaker/health aide service three times a week. The regular contact from a case manager remains an important part of the care plan.

What Can Be Learned from the Social HMO Demonstration

An important issue for the Subcommittee and for all those involved in developing public policy in this area is to define what you can expect to learn from the Social HMO demonstration. The evaluation protocol is currently designed to assess whether Social HMOs meet their objectives from the perspective of consumers, providers, and government. The following are some of the questions that you will be able to answer in the future as you develop long-term care policy.

1. Are access and continuity of care improved through case management?

2. Are expanded long-term care benefits a primary cause of enrollment?

3. Is quality comparable in a Social HMO setting?

4. Will the increased availability and use of outpatient and community services result in lower inpatient utilization?
5. Will total costs for Medicare, Medicaid, the Social HMO, and the beneficiaries be reduced?

The Social HMO demonstration provides an excellent opportunity for all of us to learn more about these issues. Those of us involved in that effort are grateful for this Subcommittee's continued leadership, and look forward to continuing to work with you. Thank you.

SENIORS PLUS

PREVENTIVE SERVICES

BENEFITS AND SERVICES	YOUR PRESENT MEDICARE	SENIORS PLUS
MEDICAL SERVICES AND SUPPLIES		
Routine physical exams	You pay 100%. Routine preventive health care services not covered by Medicare.	You pay nothing.
Cancer screening (routine screening based on American Cancer Society guidelines)	You pay 100%.	You pay nothing.
Routine foot care	You pay 100%.	You pay nothing for hygienic care, care for symptoms of flat feet, removal of calluses, corns and warts.
Routine eye examinations and eyeglasses	You pay 100%.	You pay nothing for routine examinations. One pair of eyeglasses from a specified selection provided with 50% co-payment every two years or when a Group Health Inc. ophthalmologist or optometrist finds that your prescription has changed significantly. Contact lenses provided free when medically necessary.
Routine hearing exams and hearing aids	You pay 100%.	You pay nothing for routine examinations. One hearing aid provided with 50% co-payment every two years if needed. Initial fitting sessions covered in full. You must select from Group Health Inc.'s selection of hearing aids.
Immunizations	You pay 100% for routine preventive immunizations except for pneumococcal vaccine. You pay 20% for immunizations required as a result of injury or direct exposure to infectious disease.	You pay nothing.
Dental care	You pay 100% for routine dental care.	You pay nothing for preventive and diagnostic care including exams, x-rays and cleaning every six months. This includes cleaning of dentures. You can obtain additional care for teeth and dentures with a 20% discount at Group Health Inc. facilities.
Office visits	You pay $75 deductible per calendar year plus 20% of Medicare allowable charges. If services cost more than Medicare allowable charges, you pay 100% of the difference.	You pay nothing.
Medical & surgical care		You pay nothing.
Diagnostic tests & treatment		You pay nothing.
Laboratory & X-ray tests		You pay nothing.
Radiology & Pathology		You pay nothing.
Dressings, splints & casts		You pay nothing.
Inpatient physician & surgical services		You pay nothing.

	BENEFITS AND SERVICES	YOUR PRESENT MEDICARE	SENIORS PLUS
	Dental/Medical Care	After deductible, you pay co-insurance for surgery of the jaw and related structures, treatment of oral infection and dental procedures that are integral parts of medical procedures.	You pay nothing for surgery of the jaw & related structures, treatment of oral infection & dental procedures that are integral parts of medical procedures.
OTHER SERVICES AND SUPPLIES	Durable medical equipment & prosthetic devices	Medicare deductible and co-insurance apply.	You pay nothing when equipment or device is prescribed & selected by a Group Health Inc. physician.
	Blood & blood derivatives	Three pints deductible.	You pay nothing. Three pints deductible eliminated.
	Physical therapy	Medicare deductible and co-insurance apply.	You pay nothing for services as defined by Medicare guidelines.
	Occupational therapy	Medicare deductible and co-insurance apply.	You pay nothing for services as defined by Medicare guidelines.
	Speech pathology services	Medicare deductible and co-insurance apply.	You pay nothing for services as defined by Medicare guidelines.
	Radiation therapy	Medicare deductible and co-insurance apply.	You pay nothing.
	Prescription drugs	You pay 100%.	You pay $2.00 for up to a 34-day supply of prescription drugs when purchased at a Group Health Inc. or Group Health Inc.-approved pharmacy.

INPATIENT SERVICES

HOSPITAL INPATIENT CARE	Semi-private room,* meals, special diets	Coverage limited to 90 days per benefit period. You pay deductible for first 60 days. You pay co-insurance per day for 61-90 days. Then for 60 day lifetime reserve you pay higher co-insurance per day. You pay 100% after this is used up. (*Private room covered if medically necessary.)	You pay nothing for unlimited days, as authorized by a Group Health Inc. physician. (*Private room covered if medically necessary.)
	Operating room, special care units		
	Laboratory tests		
	Nursing services		
	Necessary medical supplies and use of appliances		
	Drugs furnished by hospital		
	Medical social services		
	Blood & its administration	Three pints deductible.	You pay nothing.

Federal Medicare officials estimate that co-payment and deductibles under basic Medicare coverage will cost the average Medicare beneficiary $33.87 per month in 1985. Your SENIORS PLUS membership will provide coverage of all co-payments and deductibles plus coverage of all extended benefits listed in this brochure.

BENEFITS AND SERVICES	YOUR PRESENT MEDICARE	SENIORS PLUS
SKILLED NURSING FACILITY CARE		
Semi-private room,* meals, special diets	For care that meets specific Medicare criteria for coverage. For additional SENIORS PLUS benefits, see Long-Term Care section.	
Nursing services		
Drugs furnished by skilled nursing facility	Coverage limited to 100 days per benefit period and only if it follows hospital stay of at least 3 days. You pay nothing for the first 20 days. You pay co-insurance per day for days 21-100.	You pay nothing for unlimited days, as authorized by a Group Health Inc. physician. (*Private room covered if medically necessary.)
Necessary medical supplies		
Physical, occupational and speech therapy		
Use of appliances and equipment furnished by the facility (such as crutches, braces and wheelchairs)		
Medical social service		

HOME HEALTH CARE SERVICES

	For care that meets specific Medicare criteria for coverage. For additional SENIORS PLUS benefits, see Long-Term Care section.	
Skilled nursing & home health aide services	You pay nothing for unlimited visits.	You pay nothing for unlimited visits.
Occupational speech and physical therapies	You pay nothing.	You pay nothing.
Medical social services	You pay nothing.	You pay nothing.
Medical supplies & equipment furnished by the home health agency	You pay nothing.	You pay nothing.

LONG-TERM CARE SERVICES

Total benefit package		SENIORS PLUS will pay up to $5000 for any combination of long-term care services provided during each contract year. You pay 20%, we pay 80% up to our $5000 limit. Nursing home coverage carries a $6500 lifetime limit.
Custodial care in a skilled nursing facility or intermediate care facility	You pay 100% for custodial care at home or in a nursing home. Not covered by Medicare.	Covers any nursing home stay including respite care in a plan-approved facility. Subject to co-payment and benefit limit listed above.
In-home support services		Subject to co-payment and benefit limit listed above. Includes all home health services beyond current Medicare guidelines, homemaker, medical transportation, adult day center services, emergency response communication systems, and maintenance level physical, occupational and speech therapy.

	BENEFITS AND SERVICES	YOUR PRESENT MEDICARE	SENIORS PLUS
	Service Coordination	Not provided by Medicare.	Provided for all members receiving long-term care services listed above. Individualized assistance with planning and coordinating the full range of needed services, including non-covered services such as home delivered meals or chore services. A special contract with Hennepin County allows Service Coordinators to arrange additional homemaker and chore services to eligible members.
	MENTAL HEALTH AND CHEMICAL DEPENDENCY CARE		
INPATIENT	Inpatient mental health care for crisis-intervention and short-term psychotherapy	Coverage same as Hospital Inpatient Care with 190 day lifetime limit in psychiatric hospital.	You pay nothing for up to 90 days per benefit period plus any of your remaining 60 lifetime reserve days. Unlimited number of benefit periods.
	Semi-private room and necessary services and supplies		
OUTPATIENT	Services of psychiatrists, psychologists & mental health counselors	You pay $75 deductible. Coverage limited to $250 per year.	You pay only $10 per visit for up to 20 visits per calendar year.
	Chemical dependency treatment	You pay deductible.	You pay nothing for treatment given or authorized by Group Health Inc. providers through formal outpatient chemical dependency programs.
	IN-AREA EMERGENCY SERVICES		
	Emergency services from hospital or physician in service area Ambulance	You pay regular Medicare deductible and co-insurance as described in Hospital and Medical Services sections above.	You pay nothing. You should notify Group Health Inc. as soon as possible.
	OUT-OF-AREA COVERAGE		
	Emergency or urgently needed care to treat illness or injury including inpatient hospital and physician	You pay regular Medicare deductible and co-insurance as described in Hospital and Medical Services sections above.	You pay 20% of the first $500, then you receive same coverage as physician and in-patient services above (anywhere in the world).
	Ambulance	You pay regular Medicare deductibles as described in physician services listed above.	Outside of service area, Group Health Inc. pays 80% of the fair and reasonable charge; remaining 20% is member co-payment.

LOCATIONS

Choose from 14 convenient medical centers.

Apple Valley Health Center
15290 Pennock Lane
(150th Street & Cedar Avenue)
Apple Valley, MN 55124
431-7070

Bloomington Medical Center
(with Dental)
8600 Nicollet Avenue
Bloomington, MN 55420
884-1150

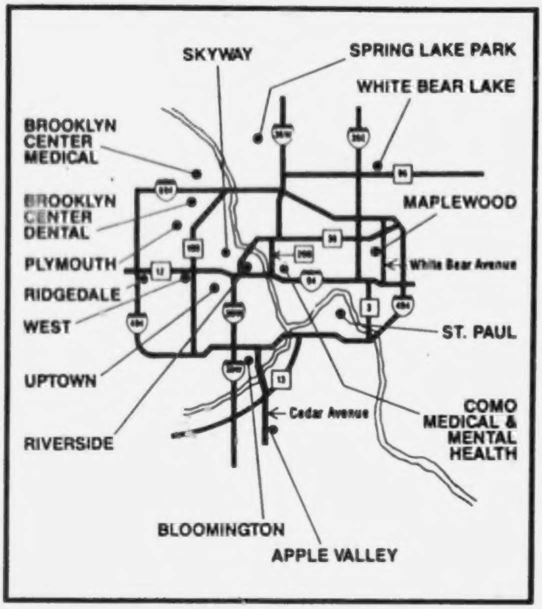
Brooklyn Center Dental Center
5901 John Martin Drive
Brooklyn Center, MN 55430
566-3770

Brooklyn Center Medical Center
6845 Lee Avenue North
Brooklyn Center, MN 55429
566-9500

Como Medical Center
(with Dental)
2500 Como Avenue
St. Paul, MN 55108
641-6200

Maplewood Medical Center
2165 White Bear Avenue
Maplewood, MN 55109
779-1500

Mental Health Center
1605 Eustis Avenue
St. Paul, MN 55108
646-0610


SKYWAY
SPRING LAKE PARK
WHITE BEAR LAKE
BROOKLYN CENTER MEDICAL
BROOKLYN CENTER DENTAL
MAPLEWOOD
PLYMOUTH
White Bear Avenue
RIDGEDALE
WEST
ST. PAUL
UPTOWN
COMO MEDICAL & MENTAL HEALTH
Cedar Avenue
RIVERSIDE
BLOOMINGTON
APPLE VALLEY

Plymouth Medical Center
Four Seasons Shopping Center
4220 Lancaster Lane
Plymouth, MN 55441
559-1707

Ridgedale Medical Center
14001 Ridgedale Drive
Minnetonka, MN 55343
546-2500

Riverside Medical Center
(with Dental)
Fairview/St. Mary's Medical Office Bldg.
606 24th Avenue South
Minneapolis, MN 55454
371-1600

St. Paul Medical
(with Dental)
205 South Wabasha
St. Paul, MN 55107
224-3711

Skyway Medical Center™
(with Dental)
701 Fourth Avenue South
Minneapolis, MN 55415
333-1800

Spring Lake Park Medical Center
(with Dental)
1415 81st Avenue N.E.
Spring Lake Park, MN 55432
780-1551

Uptown Medical Center™
Calhoun Square, second level
Lake Street & Hennepin Avenue
Minneapolis, MN 55408
822-4500

West Medical Center
15[illegible] Utica Avenue South
(Highways 12 & 100)
St. Louis Park, MN 55416
544-9571

White Bear Lake Medical Center
1430 Highway 96
(Highway 96 & Birch Lake Road)
White Bear Lake, MN 55110
426-1980

AN IMPORTANT REMINDER

All hospital and physician services (except the emergency services and urgent care outside the service area) must be provided by, or arranged and authorized by a Group Health Inc. physician. Long-term care services must be authorized by a SENIORS PLUS Service Coordinator.

EMERGENCY SERVICES: Includes medical care received under this Plan inside or outside the SENIORS PLUS service area which is required as a result of the sudden, unexpected onset of illness or injury which if left untreated or unattended would result in the serious impairment of the member's health or death.

URGENTLY NEEDED CARE: Includes benefits covered under this Plan while the member is temporarily outside SENIORS PLUS service area which are required in order to prevent a serious deterioration in the member's health and which cannot be delayed until the member returns to the service area.

REPRESENTED SPECIALTIES

- Allergy
- Cardiology
- Child Development
- Child Psychiatry
- Dermatology
- Endocrinology
- Family Practice
- Gastroenterology
- General Surgery
- Hematology
- Infectious Diseases
- Internal Medicine
- Neonatology
- Neurology
- Obstetrics and Gynecology
- Occupational Medicine
- Oncology
- Ophthalmology
- Orthopedic Surgery
- Pediatrics
- Pediatric Cardiology
- Pediatric Endocrinology
- Pediatric Hematology
- Pediatric Oncology
- Psychiatry
- Pulmonary Medicine
- Reproductive Endocrinology
- Rheumatology
- Urology

SERVICES AND SUPPLIES NOT COVERED

- Unauthorized care obtained from a non-Group Health Inc. provider except for emergency services anywhere or urgently needed care outside the service area.
- Care obtained outside the service area which could have been anticipated before leaving the service area.
- Cosmetic surgery, unless Group Health Inc.'s Medical Director finds it to be medically necessary.
- Elective procedures which are not determined to be in a member's best interest.
- Vocational, recreational, and educational therapy.
- Mental health treatment requiring more than 20 outpatient visits.
- Organ or bone marrow transplants and other experimental procedures, (except kidney and corneal transplants).
- Custodial care in a skilled nursing or intermediate care facility only partially covered as explained in brochure.
- Equipment which modifies a home or automobile.
- Food supplements which are not medically necessary in Group Health Inc.'s judgement.
- Travel.
- Personal or comfort items during inpatient care (e.g. TV, telephone).
- Dentures in almost all cases.
- Orthopedic shoes (unless part of brace) or foot supports.
- Private duty nursing.

A list of primary care and specialty physicians on the staff of Group Health Inc., as well as a list of affiliated hospitals is available from our marketing department.

We encourage members to give us their comments on the services they receive under the SENIORS PLUS plan. While we hope our service will always be satisfactory, we do offer members a mechanism through which complaints may be formally resolved. This complaint procedure is designed to resolve disputes between members and Group Health Inc., or Ebenezer Society, or between members and hospitals or physicians who provide services under the SENIORS PLUS plan.

If a dispute is not resolved to the satisfaction of the member, the member is entitled to appeal through Medicare's reconsideration and appeal process. See your Medicare handbook for details.

FOR MORE INFORMATION CALL 623-8600

CASE STUDY #1
Caregiver Support and Alzheimers

Mr. & Mrs. S. are in their 70's and are both members of Seniors Plus. Mrs. S. is a 72 year old woman with a severe Alzheimer's-type illness. She lives in an apartment with her husband, who provides 24 hour care. She cannot be left unsupervised even for short periods of time. She requires assistance with bathing, dressing, and needs reminders and supervision for eating and all other activities. Mrs. S. frequently attempts to leave the house on her own and on several occasions has wandered the streets for hours before the family or police have been able to find her. The husband literally has to lock the two of them into their bedroom at night to prevent her from leaving when he is asleep. She is in excellent physical health and is a large, strong-willed woman. When persons other than her husband attempt to prevent her from wandering, she becomes combative and has become physically assaultive.

The Seniors Plus program provides Adult Day Care to Mrs. S. three days per week as a way to both provide role relief to the husband and to keep Mrs. S. involved with other people and activities. Recently Mr. S. needed hospitalization for major surgery. Seniors Plus provided nursing home coverage for Mrs. S. during that period. When Mr. S. returned home, Mrs. S. left the nursing home and also returned home. Seniors Plus increased Adult Day Center service to daily and provided homemaker service for Mr. S. during his recovery period. Mr. S. has now resumed his role as homemaker and caregiver. Mrs. S. continues at Day Center for three days a week. A Seniors Plus case manager remains involved with both of them to monitor their progress and to help Mr. S. plan for the expected decline in Mrs. S. due to the nature of her Alzheimer's-type illness. The case manager arranged for Mr. S. to attend a Caregiver Support group coordinated by Ebenezer, a co-sponsor of Seniors Plus. At those sessions Mr. S. learns about caring for a disabled person and about taking care of himself. He has a chance to talk with other caregivers in similar situations. Mrs. S. sees her Group Health physician on a regular basis. With the consultation of a geriatrician, an attempt is being made to use medication to help control her agitation and combativeness without impairing her energy or ability to participate in activities. If Mr. and Mrs. S. did not receive the services offered through Seniors Plus, it is likely that either Mrs. S. would be in a nursing home or Mr. S. would have postponed surgery or otherwise ignored his own health concerns.

The monthly cost of the care plan for Day Care for Mrs. S. is $322. Seniors Plus pays 80%. The extra cost for the short-term nursing home stay, additional day care, and a week of homemaker service was $1435. Seniors Plus covered 80% of that one-time expense.

CASE STUDY #2
Living Alone With Support

Mrs. W. is a 70 year old single woman who lives alone and has no family in the area other than a sister in a nursing home and an older brother. Her health problems include Parkinson's Disease, heart trouble, hypertension, and severe curvature of the spine (scoliosis). She has problems with dressing, bathing, and daily grooming tasks. She is unable to do routine housekeeping tasks or meal preparation. Her brother helps with grocery shopping and transportation but is physically unable to provide the other services. Mrs. W. has an outgoing personality and is determined to remain in her own home for as long as possible. She is also realistic about her limitations and knows that a decline in her present condition may limit her ability to remain independent.

Mrs. W. receives daily homemaker and health aide service from Seniors Plus. Because of the program's flexibility with criteria and regulations, those two services are provided by the same staff person. The homemaker/health aide stays only two to three hours a day to help with personal care and housework. Mrs. W. can manage alone the rest of the day. Seniors Plus arranged and covers the cost of the Lifeline Emergency Response System so Mrs. W. can call for help if she has a fall or cannot reach a telephone. She receives home delivered meals for her main hot meal of the day. She attends day center twice a week because she otherwise would be extremely isolated. A nurse at the day center monitors her health conditions. She also sees her physician on a regular basis for regulation of her medications.

Mrs. W. would need nursing home care if she did not have Seniors Plus services available to her. Her income is limited and she could not afford the service she receives if she were on a private pay system. If she entered a nursing home, she would be on Medical Assistance within 90 days.

The cost of Mrs. W's care plan will exceed the Senior's Plus annual limit of $5000 within about a ten month period. The Jewish Community Center where she attends day center agreed to subsidize that service for her to help stretch her Seniors Plus benefit limit further. During the two month period before her coverage is renewed, she will be on a private pay basis for the home care plan. Her case manager will help her plan to handle that. Because of Mrs. W's low income, the case manager will most likely be able to arrange subsidized fees. The case manager will remain in close contact with Mrs. W. and assist with all necessary arrangements even during the period that the long term care benefit cap has been exceeded. That is a critically important service in this situation.

The total cost of the care for Mrs. W. plan is approximately $995/month. Mrs. W. pays a private contribution for the home delivered meals and a 20% co-payment on the other home care services. The Jewish Community Center subsidizes her day center service. The monthly cost to Seniors Plus is $566. If Mrs. W. were in a nursing home on Medical Assistance, the average area monthly cost would be $1,478.

CASE STUDY #3
Unstable Health Status

Mrs. G. is an 88 year old widow living in a senior high rise. Her health conditions include pernicious anemia, hypertension, and occasional nocturnal incontinence. The housing manager reports some concerns and observation of mild memory loss and confusion. A niece assists with transportation and money management but is not available or willing to assume more responsibility. At the time she enrolled in Seniors Plus, Mrs. G. was doing her own housework and personal care. The housing manager reported Mrs. G. was relying on other tenants in the building for support and the tenants were becoming both concerned and "burned out".

Soon after her enrollment, Mrs. G. was taken to the Emergency Room due to complaints of severe back pain and sudden inability to walk. A physical exam and x-rays indicated no fractures or explanation for the pain. Hospitalization was discussed but ordinarily would not be indicated. Because of Mrs. G.'s frailty and the fact she lived alone, it was not felt she should be sent home. She was admitted to Ebenezer's Caroline Center, a transitional care SNF facility. Because of the flexibility within the Seniors Plus benefit package, the admission was covered as "in lieu of hospitalization" which would have been the only reasonable alternative in this case due to the sudden onset of the problem. While in the Caroline Center, Mrs. G. received further evaluation of her situation from her Group Health physician, who also ordered physical therapy treatments. Her mental confusion increased, which sometimes happens with the stress of physical illness and change. Mrs. G. was transferred to an Ebenezer intermediate care facility for a period of observation and to attempt to stabilize both her physical and mental health. Her ability to return safely home was questionable. Mrs. G.'s wish was to return to her apartment and her physician supported that goal. As she improved, her mind cleared. A physical therapist took her to her apartment for a visit to evaluate her ability to function safely. A home care plan that included homemaker/health aide service and maintenance home physical therapy treatments was established through her case manager. Mrs. G. is now home. Her case manager keeps in close contact to monitor her situation. She still shows mild signs of mental confusion and poor judgment. She recently purchased $2000 in hearing aids from a door-to-door salesman without realizing she has coverage for that service under Seniors Plus. The case manager was able to work through Legal Aid to get the contract cancelled.

Mrs. G's ability to remain at home is fragile and depends largely on her mental status. Her home care plan has now been able to be reduced to homemaker/health aide service three times a week. The cost of the plan is around $400/month with Seniors Plus covering 80%. The regular contact from a case manager remains an important part of the care plan.

Mr. **Wyden**. Mr. Lewis.

STATEMENT OF LLOYD W. LEWIS

Mr. **Lewis**. Thank you very much. I very much appreciate this opportunity to speak on behalf of my own institution and perhaps on behalf of my industry.

My industry might be characterized as representing 600 communities across the country. We refer to them usually as continuing care retirement communities, rather than life care, because of some unfortunate connotations coming out of the past on life care. But our industry within that, I represent perhaps a segment which might involve 200 of that 800. We indeed provide, what we believe provide, a health care policy which will cover the needs, including long-term care needs of the people living in our communities for the rest of their lives.

In my own two communities in Kennett Square, PA, which I run, we have 750 older people living in those communities. We have been operating the oldest one for 13 years. The average age of our residents when they came into our communities was 75, and I understand that this is pretty much characteristic of communities across the country.

The average age of each cohort that enters every year since then has been 75. However, at Kendal today the average age, 13 years later, is 82.8, and at Crossland it is 80.8. The fastest growing segment of our community population age group is that of those over 90 years of age.

We have drawn our people from around the Northeast. We get 50 percent from around the Wilmington and the Philadelphia vicinities, since Wilmington is our closest city. We draw 15 percent of our population from New England, 15 percent from New York, and 15 percent from Washington, DC, the balance coming from scattered around the country.

Contrary to what Mr. Waxman said—he pained me a little bit when he said that we were serving the very wealthy part of the older population of the United States. We like to believe that we are serving the middle-income group, with a scattering of representation from both lower middle income and higher. We believe that our community represents a blending of incomes, and indeed it does, though, represent a group of people who have planned out the balance of their lives.

We expect that when they come in at the average age of 75, they will live with us for 13 to 14 years. The income levels may range anywhere from $13,000 to $14,000 up to in excess of $100,000, with the average being much closer to the $35,000 range, less for a single person, maybe about that or a little bit more for the couples that we have living with us.

The rate structure of our community is such that at the present time when an older person moves from living in the residences, the independent apartments, their rates for long-term care do not change. Today we charge our residents $923 a month for long-term care, but that is following out the policy that they have purchased from us. The entry fee into our community and the sum of all the monthly fees that that average resident will pay should cover that cost of that long-term care program.

Our particular program is a fairly inclusive one. It includes independent living, meals, personal services, such as some laundry services, but housekeeping services. It includes food. More importantly, it covers a very detailed and planned health care program, which includes physician services, acute care in hospitals, and then most important of all, various levels of long-term care, from personal care, intermediate care, and skilled care.

We do include drugs in our program, so that for $923 a month, after a resident has made an entry fee to live in our community, they get a very, what I consider a very affordable quality of life. In fact, I think that the quality of care in continuing care communities in this country, quality of long-term care, is exceptionally high.

We do use the Medicare system. We do not use the Medicaid system in our means.

Medicaid—our residents, since they never spend down their entry fees, and have that contract with us, they always have an asset which is available to them, and thus they never become eligible for Medicaid. We use Medicare to cover physician services, for acute care and for less than 10 percent of the long-term care costs that we incur.

The DRG system has not had any effect on how we operate. Generally speaking, we have always been interested in getting back our patients from hospitals before the DRG limitations come into play anyway. Our experience—and in this I join very much with Jack Rowe and his comments about agism and about the effect of agism on our education of professionals in the health care field. It has not just affected physicians. It affects nurses, social workers, MBAs, people who are going to run facilities, and every other OTPT.

We do not train our professionals for working with geriatric patients. There has been a big change in this in the past 5 years, but it is just in the last 5 years. Prior to that, it was extremely hard to find a geriatrician, and it was extremely hard to find a really qualified geriatric nurse. That is changing rapidly, I am happy to report, but not rapidly enough.

I think I could probably close my comments with that, and say that I certainly would support—I think that our concept qualifies for really intense study, further study, because much of our data, with only 200 or 600 communities, depending upon how you define them in the country, the data base is not sufficient to come to any really great conclusions. We, for instance, could tell you that we believe our residents live 3 or 4 years longer on the average than people who do not come to our communities, but I must confess to you that that is an anecdotal conclusion, and not necessarily sustained by really good research. That research is in the works now, so hopefully we will have that before long.

Thank you very much.

[Testimony resumes on p. 150.]

[Mr. Lewis' prepared statement follows:]

Statement of

LLOYD W. LEWIS
Executive Director
Kendal-Crosslands

My name is Lloyd W. Lewis. I would like to thank the members of the subcommittee for inviting me here today to testify. I am Executive Director of Kendal-Crosslands, a non-profit corporation whose board of directors is made up of members of the Religious Society of Friends (Quakers). Among other projects serving the aging, we operate two continuing care retirement communities (CCRCs) in Kennett Square, Pennsylvania, serving approximately 750 older people and providing employment to 500 full- and part-time employees. Kendal at Longwood, our first community, has been in operation since October 1973 and Crosslands has been open since September 1977.

We are members of the Pennsylvania Association of Non-Profit Homes for the Aging, an organization of over 250 non-profit agencies serving over 32,000 older Pennsylvanians, and providing employment to over 17,000 people. Approximately forty of our members are CCRCs. I serve on the board of directors of this association.

We are also members of the American Association of Homes for the Aging (AAHA) located here in Washington. AAHA represents over 2,700 non-profit organizations that serve 500,000 older Americans. Of its 2,700 members, over 500 are continuing care facilities. I serve on the House of Delegates, AAHA's governing body. I also serve on the Executive Board and am chairman of AAHA's CCRC committee. In addition, I chair the Continuing Care Accreditation Commission, an independent body within the AAHA structure, designed to assure consumers that accredited facilities meet its established standards and promote high quality services. This commission is under development and its programs should be ready for national implementation early in 1986.

I am here today to tell you about my own two communities and how they meet the needs of the 750 individuals living there. We have many religious beliefs represented among our residents, virtually a spectrum of the American scene but, alas, have a relatively small number of black residents at the present time.

We maintain a single waiting list for our two communities, with present reservations of over 950 for future apartments. This is a fair number for occupancy past the year 2000. A substantial number of these will represent second generation residency in our facilities.

The average age at entry for each of our communities was 75, and the entering cohort each year thereafter has been approximately 75. The average resident is expected to be with us approximately 13 years. The average age at Kendal is 82.3 and at Crosslands, 30.8. We do not know how high the average age might climb but we do know that the over 90 group is the fastest growing segment of our resident population.

We generally serve the middle income group of our society. The vocations represented among our residents are chiefly from the helping professions (teachers, librarians, social workers, nurses, doctors, etc.). We understand that this is true for most other communities in the U.S.

The type of contract we offer our residents is fundamentally a health care annuity covering residence, food, a range of health care services (most importantly, long term care) and other amenities for the balance of residents' lives. We represent the traditional segment of the CCRC industry, offering a comprehensive range of services under continuing care contracts. The costs of health care are shared by all residents regardless of their need, and insures the availability of very high quality long term care whether each resident needs it or not. In this way, we are able to guarantee service to our residents at the same cost they would be paying for their living accommodation, even if they require nursing care for many years.

This sharing of cost among residents represents an asset that individual residents can never spend down, so they can never become eligible for Medicaid. Indeed, a modest number of our residents are receiving financial aid from funds we have reserved for this purpose. However, a much larger number would have spent down their assets if they were not in a CCRC and become dependent upon the Medicaid system. Avoiding this eventuality motivates many of our residents to come to Kendal-Crosslands.

It is also true that few of our residents, as independent puchasers of health care services on the open market, would find facilities offering the quality of care offered in our health centers at affordable prices.

We do use the Medicare system to cover basic physicial services, after the deductible amount is used, and for most of our acute care (hospital) costs. However, less than one in ten days of long term care we provide is covered by Medicare. We understand that Medicare spends far fewer dollars on our residents than on others of the same age who reside outside of CCRCs. This is not a fact verifiable by me, but is easily understandable; for we have always sought to get our residents back as quickly as possible from hospitals where major Medicare dollars are spent. For this reason, the new DRG system has not had an impact on our relations with the hospitals we use.

Another explanation for this seemingly good cost experience is the planned continuity of care that we offer our residents. Through our clinic services, we plan, oversee and coordinate a full health program, tailored for each individual resident. The kind of attention and oversight achieved for our residents in their approximate 13 year stay with us is rare for our society and even more rarely affordable.

Perhaps this service is at the heart of why our residents seem to live longer than comparable cohorts outside CCRCs. This fact is verified by the actuarial statistics we keep to calculate our morbidity and mortality experience.

This brings me back to the contract we sign with our residents and the rates we charge. Again, we look upon our contract as essentially a long term health care contract--with extensive social features. We charge an entry fee of $23,000 - $91,000, and a monthly fee of $923 for an individual to $2,029 for two people (depending upon the size of the unit chosen). The sum of the entry fee and all monthly fees paid to us will roughly cover the costs of the many services we deliver to them. We keep pace with inflation by being able to raise monthly fees for current residents and entry fees for new residents. Managing this system calls for considerable financial sophistication and the concept is not easily understood. However, the continuing success of most of our industry bears testimony to the fact that we have learned to manage these many factors.

The essential ingredients our communities offer residents are security, sociability, independence, autonomy, a specially designed environment, continuity of health service, and high quality care.

Incidentally, we believe some of the highest quality of long term care in the U.S. today is offered in CCRCs. It is where we lavish our attention and dollars, but we can afford to do that in these contained, moderate-sized, manageable units. In our own communities, we are proud of the fact that we do not confine or segregate confused people (mostly victims of Alzheimer's disease). We have never owned or used physical or mechanical restraints on our residents in our health centers. Perhaps these factors contribute to the kind of atmosphere that has enabled our success and the long waiting list that insures our financial security.

Over the years, my staff and board have pursued a pro-active role in our field. We have worked hard for sound state legislation and regulation in Pennsylvania. We have invested years of effort into the development of an achievable, effective accreditation system. We are firm believers in an informed public and consumer. We also believe that an informed public will lead to an increasing use of the kind of community we offer. As matters presently stand, perhaps as many as 50 percent of those Americans over 65 years of age could afford some form of continuing care if they understood and accepted the concept. We serve only a small percentage of this number today.

Kendal-Crosslands is actively participating in several research projects directed at eliciting more detailed data on CCRCs. One project is aimed at designing the most affordable, possible model which would enable us to reach down the economic ladder to lower income groups. Another project, funded by the Health Care Financing Administration (HCFA) and being carried out by the Hebrew Rehabilitation Center in Boston, Massachusetts, is directed at building a substantial, national data base on critical points of operating CCRCs. We believe further research in the field is necessary and warranted.

If I may, I would like to turn to the broader picture of continuing care in the country. There are many other models in the spectrum of facilities that comprise the CCRC industry. For example, a number of CCRCs provide all the services offered at places such as Kendal-Crosslands but provide them through a contract that charges on a fee-for-service basis rather than insuring or spreading the cost over the whole community. Many of these facilities do depend upon Medicaid once a resident spends down their assets.

Other facilities use a fully refundable entry fee, which again is basically a fee-for-service arrangement but necessarily is directed at a more affluent constituency. However, as you can readily imagine, the variety of models are numerous, each with it own rationale and, for the most part, working successfully at delivering services.

The majority of these facilities have been built in the last two decades although the concept began centuries ago. Philanthropic "shelters" were set up for elderly individuals, usually sharing a common faith, where they were given care for the remainder of their lives. Through the years, these unique arrangements evolved into what we now know as continuing care. The majority of current facilities are sponsored by religious organizations, trade and professional organizations and military retirees. Approximately 95 percent of the facilities now in existence are operated on a non-profit basis.

It is estimated that 600 continuing care facilities are located throughout the country, serving 150,000 people. Although some states such as California, Florida, Pennsylvania, Illinois and Ohio have relatively large numbers of facilities, there are states that do not contain any. Contrary to the belief that most of the growth and development will be in the sun belt states, most retirees will choose to stay within a 20 minute drive of family and friends.

Size, style, and setting will vary with each facility but an average continuing care facility contains 250-300 residential units and 60-70 nursing beds, although facilities serving over 500 residents are not uncommon. Most communities are situated in a campus-like environment with a central building, nursing center and housing units set in suburban areas. Others are in high rise buildings in the center of large metropolitan areas. The residents average age upon entry is 78 and the average age of all residents is 80-82. Because women's life expectancy is longer than men's, a large number of residents are female, accounting for 55-85 percent of the resident population. The majority of residents (60-80 percent) move to facilities that are within a 25 mile radius of their home. Residents will stay in a continuing care facility an average of 12 years.

Two types of fees are paid by residents of a continuing care facility: an upfront entry fee and a monthly service fee. Entry fees vary widely depending on the type of contract and the services included in the contract. Entry fees average $50,000 and monthly fees $700-$1200, depending on size and type of accommodations. Seventy-two percent of people age 65 and over own their own homes, 34 percent of these own their homes free and clear. In most cases, the proceeds from the sale of these homes are sufficient to cover a substantial portion of the entrance fees. Private pensions, social security, savings, and income from investments are usually adequate to meet monthly fee costs. Forty percent of those 65 and over have annual incomes of $20,000, and could well afford this type of arrangement.

Services

A wide variety of services are available in continuing care facilities. Each resident has his/her own apartment; either studio, one or two bedroom, depending on the individual's needs. Each unit has its own bathroom and kitchen facilities and emergency call button. Many services such as meals, housekeeping, maintenance and laundry are included in fees, and others can be purchased on an as-needed basis. Personal care services such as assistance with bathing and dressing may be available and may or may not be included in fees. Many communities are now moving toward offering these personal care services because it enables residents to remain independent and in their apartment units as long as possible, thus delaying a permanent move to the nursing facility. Once a resident is permanently moved to the health care facility, their apartment is released and a new resident moves in. In some cases, rates in the health care center remain the same as the monthly fee being paid in the apartment, although some facilities may charge a daily rate in lieu of this monthly fee. Other facilities offer a specified number of free nursing days before a daily rate is charged.

Other services such as planned activities, transportation, library, recreational facilities, various crafts and hobbies are available in many CCRCs. For added convenience, some communities have banking services, small grocery stores, beauty salons and barber shops for residents.

All services provided by the facility are designed to help the person stay active and independent as long as possible. When and if health care services are required, the health care facility is close, an important feature especially for those residents whose spouses are located in the health care center. Visiting is convenient and many feel a great peace of mind knowing their spouse is near.

Many things in addition to the provision of such an array of services attract people to continuing care facilities. Security, independence, convenience, freedom and various social activities all are advantages of this lifestyle, but it is the access to health care that seems to be the most appealing feature for most residents.

Finally, I would like to comment upon some of the problems that have occurred in our industry. The first notable case concerned Pacific Homes, a genuine non-profit agency allied to the Methodist Church, where lack of actuarial expertise and sophistication led to bankruptcy. Far more was promised than could be delivered. In this case, fees charged to residents were increased to relect higher costs and all residents were able to remain in the facility. Such problems for projects that are related to religious groups with established constituencies are rare today.

Most financial debacles have occurred in projects where the aspirations of the developers are not based on the reality of the market. It appears that most older people feel more comfortable contracting with genuine, religiously based groups for the very intimate services characterized in continuing care. An example which received considerable national attention was a project in Philadelphia called Fiddlers Woods. Here the developer created a 501(c)(3) organization to own and operate a CCRC. A large tax-exempt bond issue of over $33,000,000 was sold and the proceeds partially used to build the facility. Unfortunately, upon completion, no one was interested in living in it and bankruptcy swiftly followed. Bondholders suffered substantial losses.

A further unfortunate consequence of this failure (and the failure of other similarly conceived projects) is that when sound projects with substantial constituencies apply for permanent financing, the failures of the ill-fated projects are cited as reason for not giving funding. That is a bitter pill to swallow for those of us who have worked for many years to develop a sound industry. We are very hopeful that the accreditation system we are developing will help consumers, government and financiers in making better decisions about CCRCs.

Our national association, AAHA has a many-pronged approach aimed at developing a healthy CCRC industry. AAHA publishes a national consumer directory giving many vital facts about existing projects. Regular, two-year up dates should keep a valuable consumer tool for helping older people find the right place to live.

AAHA is carefully monitoring the development of state regulation of continuing care. Almost twenty states now have legislation in place or are in the process of developing it. AAHA has sought to play a consultative, helpful role in this effort.

Most recently, the development of a national data base on continuing care is being planned and, indeed, has been partially launched. The collection of detailed data that can be properly collated should reveal valuable information to help all of us in further developing and refining this most promising social instrument.

And, finally, as alluded to before, the development of a credible accreditation system through the Continuing Care Accreditation Commission is already well under way. Over twenty communities have already received accreditation and rapid progress is expected over the next year.

I am most appreciative of the opportunity to testify here this morning and will remain available in the future to be of any further help if it is needed. Thank you for your courtesy and attention.

Mr. **Wyden**. Thank you, Mr. Lewis.

Ms. Ansak, my apologies for confusing your name with your program. I have heard many good things about your program, Ms. Ansak, having worked with seniors over the years.

STATEMENT OF MARIE-LOUISE ANSAK

Ms. **Ansak**. That is not unusual. I am often called Mrs. On Lok.

Mr. **Wyden**. And one could certainly do worse it seems to me, because we know of your fine program and look forward to your comments.

Ms. **Ansak**. I would like to thank you, Mr. Chairman, and the members of this committee and the excellent staff for all your support over the past years. I guess we are about the longest existing demonstration project in the United States. We started in 1971, actually 1972, with a small grant from the Administration on Aging.

At that time it was a community group that got together and decided that they wanted to do a long-term care project. It basically was a nursing homein the community. And with the help of the Administration on Aging we started a day health center.

They had an idea from the beginning to develop a continuum of care, which, I think, in the meantime has been mentioned today here, and has been mentioned many times. It is really the essence of long-term care, that we need a continuum of care, we need various models to deal with the elderly who are in the long-term care category.

After we got through with the Administration on Aging and they told us you have had a demonstration project long enough we found that in order to provide the kind of care we wanted to provide we needed also to include the medical services. Before that we were pretty much limiting ourselves to day health services to support services in the home.

We felt two things, in 1978, that in order to control the cost, and also to provide good human services, we needed to have the control over the total system. We then went to Medicare and became a project as a consolidated model of long-term care.

You just heard about the SHMOs which are similar to On Lok, except the difference is we deal only with the frail elderly, those certified for skilled nursing care. Those are the people most people are very concerned about in terms of cost.

We developed the consolidated model from 1978 to about 1983. Actually an ideal system. At that time we had Medicare we dealt with one project officer and one funding source. That was a real dreamboat. That was the ideal situation.

You didn't have to deal with 17,000 bureaucracies, but you dealt with one organization. It was cheaper, I think we can ultimately prove that, but it is not realistic.

So, in 1983 we took our system, and with the help of a very good friend who is sitting in the audience—who used to work for the Senate—and who is our Godfather—in a good sense—our consultant pro bono, Mr. Jay Constantine, we got waivers. We took our system and developed a long-term care system which is capitated, and where we assume total risk.

Since November 1983, we get reimbursed by both Medicare and Medicaid on a capitated basis and we assume total risk. I think I am happy to report that we have been able to make it, and that essentially the results of that program have been that the services have remained of high quality. The clientele we are serving is the same clientele as we served before.

We are not just taking in people who are handicapped. In fact, since DRG came into being, we have very sick people getting into the program.

We serve them in the community with the in-home services, and the day health services. We have optometry, dentistry—everything is provided for these elderly.

The participants are happy, in spite of the fact that some of them have a $1,000 copayment a month, which is very high. These are the people who have Medicare only. They have chosen to stay in On Lok.

We have seen that with this system we have been able to save Medicare and Medicaid approximately 12 percent. And what is interesting is that in spite of that, we have still been able to make some small savings, and put them in a risk reserve.

Another interesting part is that our people, who are the very frailest of the elderly, go less often to the hospital and stay shorter periods of time in the hospital. We feel that is very significant, and I think hospitalization can be reduced provided you have the backup services like On Lok has and the many different kinds of options that we can offer to prevent the hospitalizations.

I think—I have submitted a lot of documentation on On Lok; and perhaps I will stop here and hope that you will ask me some more questions.

Thank you.

[Testimony resumes on p. 174.]

[The prepared statement of Ms. Ansak and attachment follow:]

Hearings of the Energy and Commerce Subcommittee on Health and the Environment
Friday, October 18, 1985, Washington, D.C.

I am Marie-Louise Ansak, Executive Director of On Lok Senior Health Services, a community based organization involved in developing and operating a long term care program for the handicapped elderly in San Francisco's Chinatown - North Beach District.

First, I would like to take the opportunity to thank you, Mr. Chairman, and the members of your Committee for your help and support over the past years. Your most recent efforts in helping the program gain more permanent status with the introduction of H.R. 3101 is not only extraordinary for On Lok, but also a clear expression of your concern for the plight of our frail senior citizens and your willingness to make some significant changes. It is an expression of your understanding that long term care needs have to be looked at comprehensively if this country is ever to provide humane and cost effective care to the elderly in need.

The Board of Directors, staff, and participants of On Lok are relieved to know that their program will finally have a chance to survive in the years ahead. At the same time, we have a clear sense of obligation to assist, to the extent possible, other groups and organizations in developing such service systems. We are willing and eager to share our experiences with others in the country and to help develop a network of community based long term care systems willing and able to provide humane services on a capitated basis.

On Lok Senior Health Services evolved in response to the needs in and with the support of the community. Its objective is to keep people surrounded by people, not just bricks and mortar. On Lok provides services to a group of the frailest elderly - those who are certified by the California Department of Health Services as being in need of intermediate or skilled nursing care. The salient feature of On Lok is that it is an organization which provides all (or almost all) services. A multidisciplinary team assesses the needs of the sick older person and directly delivers all services - themselves or under fixed-rate contracts (with hospitals, skilled nursing facilities, medical specialists). A person referred to On Lok accepts On Lok as the only provider or intermediary. The service package includes a wide variety of services such as primary medical care, nursing care, social services, rehabilitation therapies, dietary counseling, meals, in home services, grooming, recreation, transportation, hospitalization, and, if need be, nursing home, respite care or supervised housing.

All these services are provided in On Lok's own facilities, three day health centers, clinics, a congregate housing facility and some specialized housing as well as in clients' homes and a couple of hospitals and a nursing home with whom On Lok maintains contracts.

Today, On Lok is reimbursed for these services by Medicare, Medi-Cal and private pay sources on a capitated basis. It is the first and only program in the country which accepts this capitation payment as reimbursement in full and assumes total risk for a long term care population certified as being in need of either intermediate or skilled nursing care.

On Lok has had experience in developing and operating this sytem since 1979. Since 1983 we have assumed total financial risk - in spite of this we have found

- that services have remained of high quality and highly acceptable to the participants enrolled;
- that both Medicare and Medi-Cal have saved over 12% and On Lok has still been able to build up a small risk reserve;
- that we have continued to serve only the very frail - those you would normally find in institutions;
- that On Lok participants use less hospital care - less in fact than all persons over 65 and that their hospital stays are of considerably shorter duration.

What are the chances of replicating this program in other communities?

We feel that On Lok has proven to be an excellent model of long term care for elderly living in inner cities where you will find many of the elderly poor. We feel strongly that it could, with minor modifications, be replicated in many other areas under a variety of sponsorships. The most important feature is to have control over all services and to be reimbursed on a capitated basis with freedom to use these resources as needed.

As a community based non-profit organization, we feel strongly that this sponsorship is the basis for our own success. In order to replicate this experience, however, it is important that mechanisms be developed which will give other organizations the opportunity to build up such a system. On Lok started in 1971 as an idea and slowly with the help of grants (mostly from the Administration on Aging) and later waivers from Medicare and Medi-Cal, built its present system and gained the sophistication necessary to operate this capitated model. There are community groups and organizations who would be eager to follow in On Lok's footsteps - there are even foundations anxious to assist in the development of community based long term care systems, but the federal government has to organize a rational reimbursement system which will ultimately pay for the services. Based on the On Lok experience, this system would not involve any new funds on a permanent basis, but it would redistribute what is presently being spent on the aged certified for institutional care.

Report to the Energy and Commerce Subcommittee on
Health and the Environment
Hearings on Friday, October 18, 1985
Washington, D.C.

based on Report prepared by:
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INTRODUCTION

On Lok Senior Health Services began a new long-term care demonstration in November of 1983. Called the "Risk-Based Community Care Organization for Dependent Adults," or RB-CCODA, this project extends earlier On Lok efforts to develop a comprehensive solution to long-term care service delivery and cost problems. Specifically, the RB-CCODA has added a new financing strategy -- prospective capitation payments from Medicare, Medicaid and the individual -- to the successful consolidated service delivery model created by On Lok between 1978 and 1983. Thus, with the RB-CCODA On Lok has assumed full financial risk for delivering its comprehensive service package to an exclusively nursing-home-certified population. This report addresses the impact of the new financing approach, as evidenced by the first 12 months experience under the RB-CCODA.

BACKGROUND

In the past decade, a rapidly growing aged population, escalating health care costs, and public concern with the quality of care have stimulated a number of innovations in the long-term care field. Some innovations relate to developing community-based services as alternatives to institutional care (e.g., adult day health care, home health care, in-home supportive services, etc.), others focus on structuring service delivery to improve efficient use of resources (e.g., the national Channeling Projects, California's Multipurpose Senior Service Programs, etc.), and a few incorporate new financing mechanisms, the most notable of which is prospective capitation.

Capitated financing, which originated in the 1950s with the health maintenance organization (HMO), has been credited for increasing program efficiency and reducing health care cost. However, it has also been criticized for encouraging health care providers to target the young and healthy (in other words, the low service need population), to limit services, and to lower the quality of care in order to reduce cost. Under the current fiscal crisis, applying this type of financing to health care for the elderly as a means to control cost has become appealing.

Capitated financing for care to the elderly is currently being tested in a number of areas: Diagnosis Related Groups (DRGs) for Medicare hospital reimbursement; health maintenance organizations for Medicare benefits under provisions of the Tax Equity and Fiscal Responsibility Act (TEFRA); the Social Health Maintenance Organization (S/HMO); and the Risk-Based Community Care Organization for Dependent Adults (RB-CCODA) for comprehensive health and social services. Among these innovations, On Lok's RB-CCODA is one that targets exclusively the long-term care population and incorporates capitated financing and a comprehensive approach to service delivery.

Applying capitated financing to a long-term care population raises a number of questions. Can the RB-CCODA assume financial risk for providing care? Will the cost of care be lower under capitated financing? Can cost control be achieved without sacrificing service integrity? Namely, will the program shift its target population to serve a less needy population to control service demand? Will it cut back on needed services? Will it compromise the quality of care?

THE RISK-BASED CCODA

On Lok's RB-CCODA was designed as a comprehensive approach to the multiple issues of service fragmentation, cost and quality in long-term care.

PARTICIPANT ELIGIBILITY

The RB-CCODA focuses exclusively on the frail elderly, accepting only those who are certified as eligible for nursing home care. To enroll in the RB-CCODA a person must be 55 years of age or older, live in the On Lok catchment area (the Chinatown-North Beach-Polk Gulch area of San Francisco), and be certified by Medi-Cal (California's Medicaid) as requiring an intermediate or skilled nursing facility level of care (i.e., 24-hour nursing home care). Enrollees agree to accept On Lok as the sole service provider of all health and health-related services. That is, they are "locked-in" until they choose to disenroll from the program.

SERVICE PROGRAM

The RB-CCODA adopts a consolidated model of service delivery. This model integrates within one organization all services needed by a frail population -- from inpatient and outpatient medical care, to medical specialty services like dentistry and podiatry, to social services, in-home care, meals, transportation and housing assistance. These services are under the full control of On Lok's multidisciplinary team of health and social service professionals who assess periodically each participant's needs, develop treatment plans, and provide the services or coordinate their delivery. Figure 1 summarizes the services provided by the RB-CCODA.

FINANCING

The funding of the RB-CCODA is on a prospective, per capita basis and involves the three major funding sources for long-term care -- Medicare, Medicaid, and the private sector. All-inclusive rates are negotiated annually with Medicare and Medicaid; the private share-of-cost is adjusted yearly, also. Each funding source pays a monthly capitation rate based on the individual's entitlement/eligibility. That is, if the individual has both Medicaid and Medicare coverage, these sources pay the full monthly capitation rate. If the individual is not eligible for Medicaid, he or she must share the cost with Medicare by paying the balance. A subsidy or scholarship program has been established for those who have difficulties meeting their share. Currently there is no participation by the private insurance industry (although some participants have private health care coverage).

With Section 222 (Medicare) and Section 1115 (Medicaid) waivers, On Lok is free to use the monthly capitation rate as is deemed most appropriate for participant care, without regard for the usual restrictions and rules. However, in return, On Lok bears 100% financial risk to provide all care needed by its participants. If care is provided at a cost below the negotiated capitation payments, On Lok is free to keep the savings. On the other hand, On Lok is also responsible for absorbing all cost overruns.

Thus, on one hand, the financing mechanism reflects more realistically and equitably the current cost responsibility of the traditional funding sources. On the other hand, and more importantly, the mechanism creates an explicit financial incentive for On Lok to control service utilization and the cost of care. Since the participants are "locked-in" with the program, the only means available towards cost control is to maintain their health and functional independence.

SUMMARY

Taken together, the RB-CCODA is different from traditional long-term care in which services are fragmented among individual service providers and under different funding and administrative structures. It also differs from some of the current innovations in capitated financing. Table 1 compares the RB-CCODA with current innovative programs:

- The RB-CCODA focuses exclusively on the very frail and dependent elderly, a population in need of long-term care. Whereas, HMOs funded under the TEFRA authority and the S/HMOs target the general 65+ population.
- The RB-CCODA provides a comprehensive care package covering all health and social services in out- or inpatient settings and involves Medicare, Medicaid and private funding. Whereas, the DRGs cover Medicare hospital utilization and the TEFRA HMOs cover Medicare Part A and Part B benefits; neither covers long-term care services or has Medicaid involvement.
- The RB-CCODA assumes full financial risk and sets no limits on the amount of chronic care services that can be given but relies on its multidisciplinary team to target and control service utilization. Whereas, the S/HMO limits benefits and attaches surcharges to services to control use.

Table I

COMPARISON OF SELECTED PROGRAMS WITH CAPITATED FINANCING MECHANISM

COST CONTAINMENT METHOD/PROGRAM	CLIENT POPULATION	SERVICES COVERED	SERVICE INTEGRATION	FINANCING SOURCES	PAYMENT MECHANISM
DIAGNOSIS RELATED GROUPS (DRGs)	All Medicare admissions	Inpatient hospital services	None beyond inpatient services	Medicare	Predetermined rate at discharge, based on diagnosis
HEALTH MAINTENANCE ORGANIZATIONS UNDER TEFRA	Medicare (A&B covered or B-only); half of enrollees must not be Medicare or Medicaid entitled	Medicare covered services (A&B or B-only, as contracted); additional benefits in some cases	Limited, varies depending on contract (A&B or B-only) and provider	Medicare	Prospective capitation based on 95% adjusted average per capita cost; full risk or reasonable cost contract
SOCIAL/HEALTH MAINTENANCE ORGANIZATIONS (S/HMOs)	Over 65 and covered by Medicare A&B and Medicaid	Inpatient, outpatient medical (with some limits) home health, limited chronic & mental health	Physicians arrange for acute care, case managers for chronic	Medicare, Medicaid, individuals	Prospective capitation premiums and copayments for some services; full risk or contracts
ON LOK'S RISK-BASED COMMUNITY CARE ORGANIZATION FOR DEPENDENT ADULTS (RB-CCODA)	Over 55 & state-certified as needing nursing home care	All health/health related—in & outpatient, in-home, supportive, all chronic care	Complete; assessment team delivers services	Medicare, Medicaid, individuals	Prospective capitation; assumption of full risk

THE STUDY

This study provides an initial assessment of the fiscal viability of the RB-CCODA and the impacts of the assumption of financial risk on service delivery and quality of care. The specific issues addressed include:

- Fiscal viability
  - Can the RB-CCODA reduce the service needs of participants and thus cost of their care?
  - Can the cost of the RB-CCODA remain relatively stable and comparable to the capitation rate?
  - Is the cost of the RB-CCODA competitive with that incurred by Medicare and Medicaid for a similar population?
- Impacts on service delivery
  - Has the RB-CCODA increased census as a result of efficiency concerns?
  - Does the RB-CCODA admit individuals who are relatively healthier (i.e., "cream") to lower service demand?
  - Has the RB-CCODA cut back on the medical, therapeutic, and social supportive services provided?
  - Has the RB-CCODA's quality of care been compromised as measured by the mortality rate and functional improvement of participants?
  - Is the RB-CCODA acceptable to the elderly population, particularly to those non-Medicaid eligible who must pay a share-of-cost?

Because the RB-CCODA has been in operation for only a very short time period, it is premature to assess change over time within the population or to gauge the relative impacts of the service and financing mechanism vis-a-vis a comparison group.1/ Nevertheless, much can be learned from information about the population being served, its service utilization pattern and the costs of its care. As a preliminary assessment of the impact of risk on the service population and program, this information will be compared with similar data collected from On Lok's previous project, the CCODA.

From 1979 through 1983, On Lok developed and operated the CCODA, which was similar to the RB-CCODA in every respect except its financing mechanism. The CCODA was reimbursed on a cost basis entirely by Medicare. Its service model was proven effective in improving the health and functioning of its frail, elderly clients and in maintaining them in the community. At the same time, the cost of their care was lower than that of their counterpart who received traditional long-term care (Zawadski, Shen, Yordi, & Hansen, 1984). The RB-CCODA continues this successful service model, only under prospective capitations from multiple funding sources. By comparing the two projects, the impact of capitated financing on service delivery can be assessed.

All individuals (371) enrolled in the RB-CCODA for any length of time during its first year of operation (November 1, 1983 through October 31, 1984) were included to describe the participant population and the services used, to analyze RB-CCODA's fiscal viability, and to assess the program's acceptability. However, to assess the impacts of capitated financing on the service program and its participants, a sample of the RB-CCODA study population -- the new enrollees -- was compared in terms of health and functional status, service utilization, and health outcomes to a similar sample of CCODA intakes.2/

Table 2 summarizes the demographic, health and functional status characteristics of the RB-CCODA participants. A typical participant is a 81 year old widowed woman, living alone with an annual income of $5500. She has five medical conditions and needs help in activities of daily living like bathing, grooming, and dressing.

Most of the services On Lok participants receive are provided in one of the three adult day health care (ADHC) centers. Many other services are provided to participants in their own homes. Figure 2 shows the RB-CCODA group's most heavily used outpatient and in-home services. Use of inpatient care in RB-CCODA differs considerably from that in the traditional long-term care system. The hospitalization rate of the RB-CCODA study population was lower than that of the general noninstitutionalized 65+ population (365 versus 411 admissions per 1000 per annum) and the average length of stay was also 20 percent shorter (8.3 versus 10.4 days per admission) (USDHHS, 1981). While all were certified to need nursing home care at intake and the majority still required such care, only 2 percent of On Lok's participants are in nursing homes on any one day; this utilization rate is less than half that of the general 65+ population, 4.7 percent (Liu & Palesch, 1981: 19).

FINDINGS

ANALYSIS OF RB-CCODA'S FISCAL VIABILITY

Overall Cost and Distribution among Services

During the first 12 months of the RB-CCODA, total program expenditures were $4.7 million, or an average cost of $1352 per participant per month. Over half (57%) of the RB-CCODA's cost was spent on social supportive services but only 16% of costs went for hospital and nursing home care.

Table 2

CHARACTERISTICS OF THE RISK-BASED CCDOA POPULATION

BIOGRAPHICAL DATA	
AGE	
55 - 59	0.3%
60 - 69	9.7
70 - 79	33.4
80 - 89	41.5
90+	15.1
Mean	80.7
SEX	
Male	45.3%
Female	54.7
MARITAL STATUS*	
Never married	11.8%
Married	27.1
Divorced	4.1
Widowed	53.4
Separated	35.6
ETHNICITY	
Chinese	75.4%
Caucasian	18.9
Other	5.6
USUAL LIVING SITUATION	
Alone	59.1%
With spouse only	18.2
With spouse and/or relatives	14.8
With non-relative	1.9
In supervised housing	3.4
In board and care facility	0
In skilled nursing facility	2.5
MEDIAN ANNUAL INCOME	$5484
INCOME SOURCES	
Social Security	66.6%
SSI	45.8
Pension	12.7
Investment	10.2
Family support	3.8
Other	7.5
ELIGIBILITY	
Medicare and Medi-Cal	25.0%
Medicare only	16.7
Medi-Cal only	56.8
None	0.5
Family support	3.8
Other	7.5

MEDICAL DIAGNOSES	
Nervous system/sense organ	63.1%
Cardiovascular	61.5
Mental disorder	35.8
Digestive	32.3
Endo/nutri/metabolic	28.4
Musculoskeletal	25.6
Genitourinary	22.1
Fracture	17.8
Respiratory	14.6
Neoplasm	7.3
Blood/blood forming	5.7
Infectious/parasitic	5.1
Other	29.9
Avg. # of diagnoses per person	5.0
S.D.	1.8

FUNCTIONAL IMPAIRMENT	
PHYSICAL	**% impaired**
Vision	61.0%
Hearing	45.8
Speech	19.5
Dentition	57.9
Upper extremity	50.0
Lower extremity	74.6
Bowel	35.3
Bladder	42.7
PSYCHOSOCIAL	**%impaired**
Short-term memory	72.9%
Long-term memory	67.5
Orientation	45.7
Reasoning	58.3
Attention span	47.4
Mood disturbance	77.8
Isolation	75.4
Motivation	59.4
Behavior	42.8

FUNCTIONAL INDEPENDENCE	
ACTIVITIES OF DAILY LIVING	**% needing assistance**
Eating	14.4%
Dressing	41.7
Grooming	48.7
Bathing	63.3
Toileting	33.3
Cooking	82.1
Home chore	82.9
Shopping	83.2
Laundry	80.3

* ASSESSED LEVEL OF CARE	
Social Health Maintenance	7.8%
Adult Day Health Care	20.3
Intermediate Care	58.6
Skilled Nursing Care	13.2

Distribution of Cost Among Participants

While the RB-CCODA enrolls a relatively homogenous population of institutionally certified elderly, its financial viability depends on the ability of the program to rehabilitate and then maintain some participants at a lower care level (i.e., the "social health maintenance" and "adult day health" levels rather than the "intermediate" or "skilled" nursing care levels). The savings incurred can then be applied to participants who remain at higher and costlier utilization levels ("intermediate" and "skilled"). Figure 3 shows a relative frequency and cumulative distribution of the average monthly cost of care of all participants during the first year of the RB-CCODA.

The median cost of care for each participant was $1090 per month, ranging from as low as $200 to as high as over $10,000 per month. Over 60 percent of the participants incurred monthly costs at or below the capitation rate of $1480. The remaining participants had costs higher than the capitation rate, with approximately 10 percent having costs twice the rate.

Average participant costs correlated significantly with their assessed levels of care. Participants assessed to need care at the social health maintenance level incurred an average monthly cost of only $531, those at adult day health level $1000, those at intermediate care level $1485, and those at skilled nursing care level $2371.

Cost and Rate Comparison Over Time

Financial viability also requires that the program cost remain relatively stable around the capitation rate in order to avoid any cash flow problems. Figure 4 shows the month-to-month variation of program costs as compared to the capitation rate during the first year of RB-CCODA. The mean monthly program cost was $1352 per month with a standard deviation of $164 and a range between $1039 and $1587. Cost fluctuations corresponded to hospital and nursing home utilization: the higher the inpatient utilization, the higher the cost of care.

During four of the 12 months, costs were slightly above the average capitation rate ($1480). Substantial savings in the remaining months more than covered the losses and allowed the accumulation of a risk reserve to cover future cost overruns.

Cost Comparison with Traditional Long-Term Care

For the RB-CCODA to provide a reasonable alternative to traditional long-term care, it must be cost competitive. In examining the relative cost efficiency of the RB-CCODA at this early stage, rough comparisons must serve. Information on the cost of care for a similar frail population using traditional long-term care is not readily available and On Lok's Comparison Group Study is not yet completed.

Figure 3

RELATIVE FREQUENCY AND CUMULATIVE DISTRIBUTION
OF THE AVERAGE MONTHLY COST OF CARE
(N = 370)

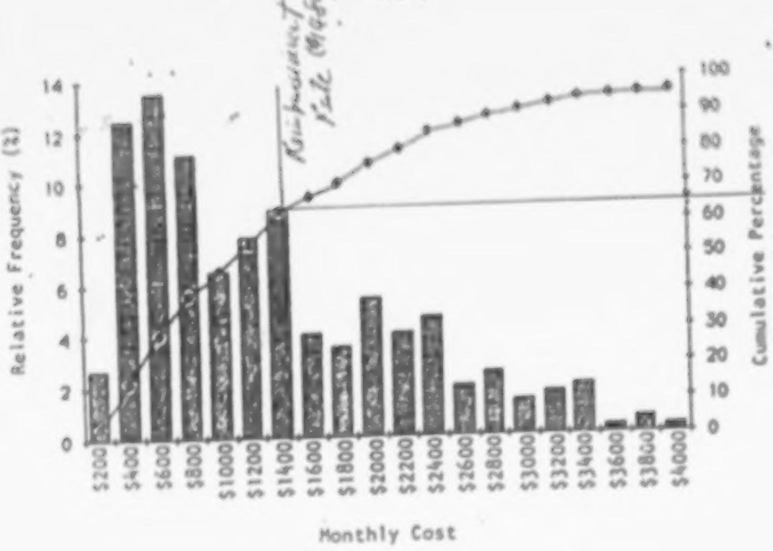
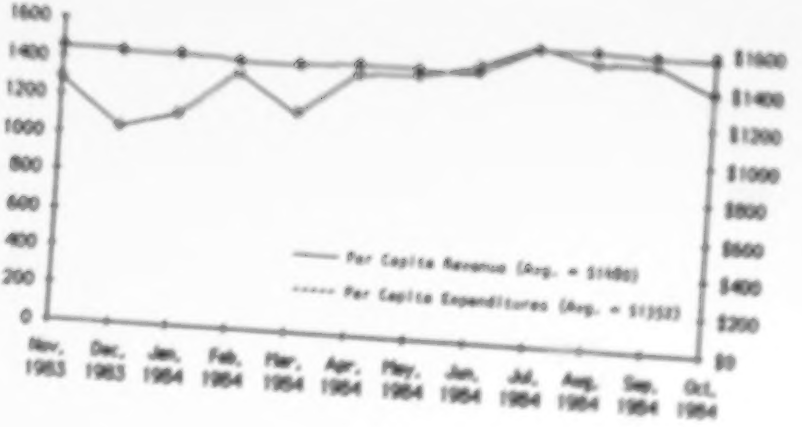


Figure 4

PER CAPITA EXPENDITURES COMPARED
TO PER CAPITA REVENUE
(11/83-10/84)



Note: The capitation rate was readjusted in July, 1984.

If the RB-CCODA were funded through traditional sources and the fee-for-service mechanism, the federal-state breakdown would be 2:3 for a typical Medicare and Medicaid eligible elderly.3/ For such participants, Medicaid would pay 42 percent of the cost; Medicare 33 percent; Title XX 18 percent; and Title III of the Older American Act 7 percent (Figure 5).

Two estimates of the cost of traditional long-term care which can be used for comparison purposes are Medicare's Adjusted Average Per Capita Cost (AAPCC) and Medicaid's nursing home rate. The AAPCC reflects average cost per Medicare beneficiary; for the San Francisco Area in 1984, the rates were estimated to be between $564 (female) and $610 (male) for a 75+ institutionalized population. Comparing the federal share of the RB-CCODA's cost (40% of $1352 or $541) with these rates showed On Lok's cost to be lower, between 89% and 96% of the institutional AAPCC.

Comparison of RB-CCODA and Medicaid cost is difficult primarily because there is no estimate similar to Medicare's AAPCC. The closest approximation was the cost of care estimated for an institutionalized population in San Francisco in 1981, $1207 (Satten, Brusstar, & O'Rourke, 1981). Although this estimate included different services than the RB-CCODA's (e.g., housing in the nursing home but only partial hospital and physician services), it probably is a fair cost benchmark. The state's share of the RB-CCODA's cost (60% of $1352 or $811) is considerably lower than this benchmark. The California Long-Term Care System Development Project (1982) provided another Medicaid cost indicator; their 1982 estimate of the monthly cost for an aged, long-term care population, was $1383, a figure also substantially higher than the Medicaid share of the RB-CCODA's cost.

IMPACT OF CAPITATION ON SERVICE PROGRAM AND PARTICIPANTS

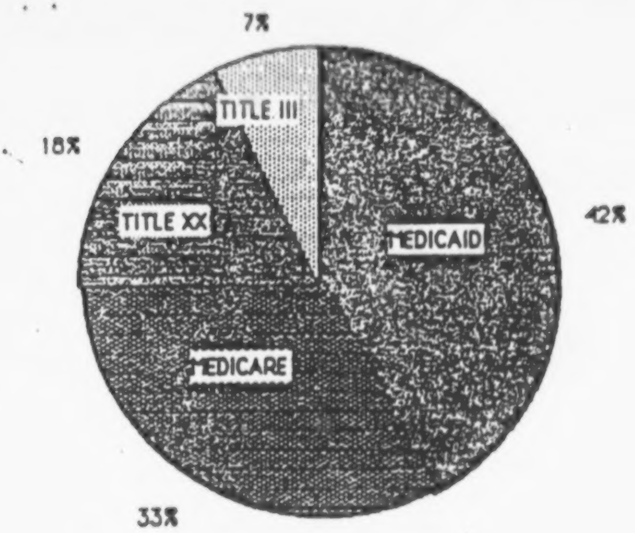
Impact on the Intake Process

Outreach efforts. Under the RB-CCODA, program financing rests on census, not on actual costs as in the CCODA. Thus, increasing program census became a more salient issue in the RB-CCODA. However, a comparison of the first 12 months of the CCODA and RB-CCODA showed no statistically significant difference in the mean number of new enrollments each month (5.8 per month in the CCODA versus 6.1 in the RB-CCODA).

Intake health and functional status. Capitated financing creates the incentive for the program to target a healthier population, i.e., to "cream," to curb the demand for services. However, on the whole, the RB-CCODA's new enrollees were as frail as intakes in the CCODA. No statistically significant differences were found between the two groups for these health and functional characteristics: sensory impairment, upper and lower extremity impairment, incontinence, cognitive impairment, dependency in activities of daily living, and instrumental activities of daily living (Table 3). Furthermore, for the most part, the proportions of CCODA and RB-CCODA new enrollees having various functionally disabling diagnoses were the same. However, the RB-CCODA group had a significantly higher proportion of fractures and other medical

Figure 5

PROPORTION OF COSTS
BY TRADITIONAL FUNDING SOURCES



Medicare/Medicaid Eligible Client

Table 3

MEAN FUNCTIONAL IMPAIRMENT AND DEPENDENCE INDEX SCORES FOR CCODA AND RB-CCODA GROUPS AT INTAKE

INDEX	RANGE	CCODA		RB-CCODA	
		N	MEAN	N	MEAN
Sensory Impairment	0 - 8	62	1.79	70	1.84
Extremity Impairment	0 - 8	62	1.97	70	2.04
Continence Impairment	0 - 8	62	1.06	69	1.20
Cognitive Impairment	0 - 15	63	5.13	68	4.07
Behavior Impairment	0 - 6	62	1.85	69	1.51
Mood Impairment	0 - 6	64	3.91	70	2.64**
Activities of Daily Living Dependence	0 - 21	62	7.27	69	5.28
Homemaking Activities Dependence	0 - 12	61	9.84	69	9.90

Note: A score of zero indicates no functional impairment or independence in activity. Lower scores indicate less impairment or dependence; higher scores, greater impairment or dependence.

$^{**}p < .01$

conditions (congenital, accident, skin and ill-defined), while the CCODA's new enrollees had a significantly higher proportion of individuals with conditions related to the nervous system/sensory organs (stroke, blind, deaf, etc.) and endocrinal/nutritional/metabolic systems (diabetes, gout, malnutrition, etc.) The RB-CCODA new enrollees were also found to be less impaired in terms of mood disturbance (anxiety, depression and social isolation).

Impact on Service Utilization

Capitated financing creates an incentive for the service program to cut costs by reducing services. Comparing the utilization patterns of newly enrolled RB-CCODA and CCODA participants revealed no significant differences in the use of outpatient therapy services (physical therapy, occupational therapy, speech therapy, recreational therapy, and nutritional counseling in the ADHC center). Hospital and nursing home utilization rates were low for both groups -- too low for their differences to be tested statistically. However, there were significant differences in the utilization of social/supportive services. The RB-CCODA group used more in-home services (attendant care, home-delivered meals, personal care, and home chore services), whereas the CCODA group used more outpatient social/supportive services (personal care, home chore services, meals and social work services in the ADHC center, and transportation). There was also a significant difference in the utilization of outpatient medical care; the RB-CCODA group used more of the services in this category (physician and nursing care in the ADHC center, drug prescriptions, lab work, x-rays, visits with the audiologist, dentist, optometrist, podiatrist and psychiatrist in the ADHC center, visits with other consultants in the community).

Figure 6 presents the findings on service utilization in the CCODA and RB-CCODA programs.

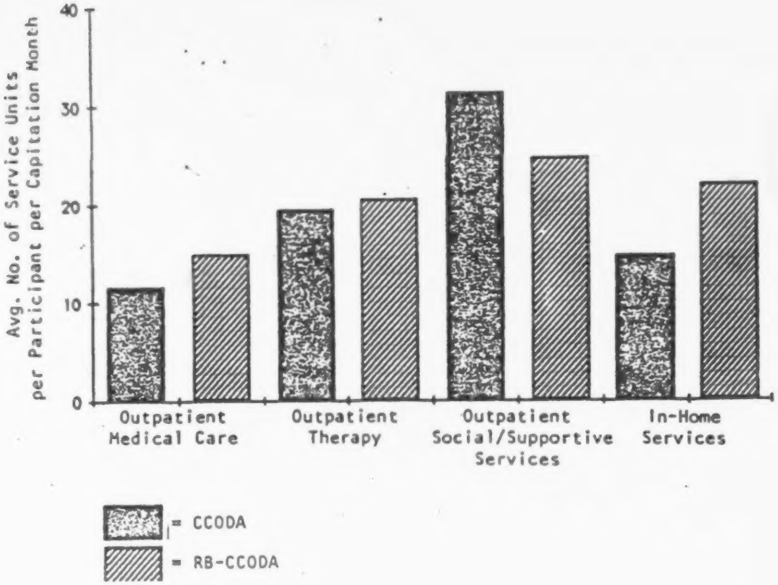
Impact on the Quality of Care

A major issue in capitated financing is quality of care. Quality in health care delivery can be measured by a range of indicators, focusing on either structure (physician qualifications, range of services, facilities, staffing), process (e.g., accessibility, continuity of care, appropriateness of care, utilization of specific services), or outcome (health outcomes, patient satisfaction outcomes). In this study, two health outcome measures -- functional improvement and mortality rates -- and one proxy measure of satisfaction -- enrollment and disenrollment -- were used.

Functional Improvement. Intake assessments for RB-CCODA and CCODA new enrollees were compared with their first three-month re-assessments to evaluate changes in health and functional status.4/ On the one hand, both groups showed improvement in the major health and functional measures, particularly in independence in activities of daily living, instrumental activities of daily living, and in mood disturbance. On the other, the RB-CCODA enrollees showed a deterioration in continence whereas the CCODA enrollees improved slightly. However, the only significant difference in the

Figure 6

COMPARISON OF CCODA AND RB-CCODA
INTAKE GROUP SERVICE UTILIZATION



changes experienced by the two groups related to mood disturbance; the CCODA enrollees improved more than the RB-CCODA intake group. Tables 4 summarizes these findings.

Mortality. The mortality rate for CCODA participants was 86 per 1000 per annum, approximately 1.6 times that for the general 65+ population (54 per 1000 per annum), but less than half that for the elderly nursing home population (186 to 276 per 1000 per annum). The mortality rate for RB-CCODA participants was 80 per 1000 per annum or 1.5 times that for the general 65+ population. There was no significant difference between the CCODA and RB-CCODA mortality rates.

Impact on Program Acceptability

Enrollment has always been used as as one indicator of the appeal of a service program to its targeted consumers. A new feature of the RB-CCODA is the introduction of a private share-of-cost for the non-Medicaid eligible elderly equivalent to what Medicaid would otherwise cover. Although this feature reflects the current public and private share of responsibility in long-term care, it was anticipated to have a profound impact on the acceptability of the program to these non-Medicaid eligible elderly.

During the first year of RB-CCODA, the program operated at its maximum capacity of 300 participants at any one time. However, a much higher proportion of the new enrollees in the RB-CCODA than in the CCODA were Medicaid eligible (70.8% versus 44.7%). Moreover, of the 27 voluntary disenrollments in RB-CCODA, 20 disenrolled due to the imposition of a private share-of-cost. Although these disenrollees constituted only 17 percent of the 120 participants required to make out-of-pocket payments, many of the others (60%) received a temporary Medicare and United Way subsidy to help pay their share.

The health status of payment-related disenrollees was compared with that of enrollees who chose to stay and pay a share of the cost. This comparison showed that those who left were younger, consistently showed less impairment, and required lower levels of care. The disenrollees also had more resources and more potential informal supports available to them as indicated by total monthly income, number of children and marital status.

SUMMARY AND DISCUSSION

During the first year of the RB-CCODA, the program remained financially solvent. The average cost of care was lower than the capitation rate. Both the cost and rate were highly cost competitive with the traditional long-term care system. Most of the cost savings resulted from the program's ability to rehabilitate and maintain participant health and thus prevent costly institutional care.

Table 4

MEAN CHANGES IN FUNCTIONAL IMPAIRMENT AND DEPENDENCE INDEX SCORES OF CODA AND RB-CODA NEW INTAKE GROUPS AFTER THREE MONTHS' ENROLLMENT

INDEX	CODA		RB-CODA	
	N	Mean Change	N	Mean Change
Sensory Impairment	52	-.08	63	-.14
Extremity Impairment	53	.42	63	.10
Continence Impairment	51	.06	60	-.13
Cognitive Impairment	54	.02	60	.30
Behavior Impairment	54	.04	61	.20
Mood Impairment	56	1.39	63	.73 *
Activities of Daily Living Dependence	54	1.94	59	.68
Homemaking Activities Dependence	52	.70	61	.69

Note: A positive value indicates a change to lesser impairment or dependency; a negative value indicates a change to greater impairment or dependency. For the scales for these indices, see Table 3.

$^*p < .05$

Furthermore, such solvency was not accomplished by compromising the service integrity of the program. The program had not "creamed" for healthier elderly in order to reduce the demand for services. Nor had it increased program census to secure more revenue, nor cut back on services to reduce cost. There had not been significant changes in mortality rate, nor deterioration in participants' health when compared to the outcome of the successful CCODA program. However, because of the private share-of-cost, the program gradually shifted through the enrollment process to having a primarily Medicaid population. Adverse selection among those with a share-of-cost was also evident.

The RB-CCODA represents a prototype of a new approach to the delivery and financing of long-term care. The first year of operation has been a period of adjustment from annual single-source funding to monthly multiple-source payments. It has also been a period of adjustment to risk-based financing in which administrative and service staff have continuously juggled quality and cost to ensure appropriate care to participants. Although it is too early to make conclusive statements about the program, it is appropriate to review and discuss two major issues of capitated financing for a long-term care population -- feasibility and acceptability.

FEASIBILITY

Is capitated financing feasible for a long-term care population? Unlike the HMOs which serve tens of thousands of relatively young and healthy people, the RB-CCODA not only has a higher cost of care, but also fewer enrollees and, because of the homogenity of the population, less leeway to spread the cost of care. The financial risk assumed by On Lok is considerable.

Nevertheless, On Lok's experience has been positive. However, the success has not depended on the capitated financing mechanism alone. Capitated financing creates the incentive to improve efficiency and to control cost but the consolidated service delivery provides the means to the end. The multidisciplinary team, the availability of resources at the team's disposal, the continuous monitoring of the participants and the experience gained through the CCODA in targetting services are key ingredients. Together these have rehabilitated and maintained the participants' health, reducing hospital and nursing home utilization to a rate lower than that of the general 65+ population.

The development of such a service delivery approach takes time and effort, but can be achieved. To On Lok, this service model is now considered as a prerequisite to the assumption of financial risk through capitated financing. Today the RB-CCODA is a complete long-term care service system integrating a service delivery and a financing model. Therefore, it can be concluded that it is feasible to apply capitated financing to a long-term care population

ACCEPTABILITY

Is the RB-CCODA acceptable to the long-term care population? The program maintained a full census of 300 participants at all times during the first year of the RB-CCODA. For most participants and their families, the RB-CCODA is a welcome alternative to institutional care. They seem to appreciate the program, support it, and choose to remain with it. However, the findings suggest that the private share-of-cost has discouraged participation of the non-Medicaid-eligible elderly.

The implementation of a share-of-cost for the non-Medicaid eligible participants reflects the current two-tier financing for health care of the elderly. On the one hand, Medicare, an entitlement program covering acute care for all 65+ elderly, does not pay for long-term care services. On the other, Medicaid pays for medical services, including long-term care, for low income elderly. Non-Medicaid eligible elderly must pay for long-term care either out of pocket or through private insurance policies, most of which provide limited coverage beyond Medicare benefits. The private insurance industry has traditionally considered long-term care as uninsurable and unprofitable, primarily because of the long-term, custodial nature of care, the potential for adverse selection, and the availability of Medicaid as a safety net. However, the growing elderly market has stimulated recently many insurance carriers to review their positions, and innovative insurance instruments are being developed and tested. As insurance coverage for long-term care becomes more available, the participation of the non-Medicaid-eligible elderly in the RB-CCODA will likely increase.

* * * * *

On Lok's RB-CCODA represents one alternative: a comprehensive, coordinated long-term care system designed with philosophical and financial incentives to maintain people in their own homes and communities as long as it is medically, socially and economically feasible. Although not conclusive, this study suggests some advantages of the model. Studies of On Lok complement those of other long-term care demonstration projects. The lessons learned from these demonstrations need to be shared and ultimately used to change health care policy and law, in order to move toward a more rational and effective long-term care system.

Mr. **Wyden**. We would, indeed.

Before I go to any questions I would like to recognize the gentleman from Utah who has a great interest in health care matters if he would like to make a statement at this time?

Mr. **Nielson**. As the oldest member of this committee in age, and one whose mother died at age 91 last November. My father only survived to 83. In my father's case we were able to care for him in his home.

In my mother's case she completely lost her memory and in the last 4 years didn't know any of her family, so I am interested in what happens in home care.

Ms. Ansak, you say that you deal with the very frail ones who normally would go to custodial care or institutions, and yet you have less hospitalization use from your patients and they stay shorter periods.

How do you do that?

Ms. **Ansak**. I think the clue to it is that we work through an intake and assessment team. We have a multidisciplinary intake and assessment team. When a person comes in he is totally assessed.

All the assets and the problems are assessed and evaluated; what can the family contribute; what additional supportive services does this family need; what kind of medical care does the person need; every aspect.

Then a treatment plan is established and everything is aranged for—we don't need to go for prior authorizations.

So, in other words, if you are talking about a very frail person, who on Friday night, all of a sudden has a breakdown, and we are not sure whether this might develop into something serious, in the traditional system generally speaking, these people have to go to an institution and be hospitalized.

We can, say instead of putting that person in a hospital, hire a home health aide or nurse and right away put that person into the home or we take the older person and put him into one of our respite care units, observe him and see what is happening. Usually with the proper kind of care we are able to cover this crisis.

That is one of the reasons why we don't send people to hospitals when they don't have to go. Frequently people are hospitalized not for medical reasons but because of uncertainty of what is going to happen.

If you have a hip fracture, traditionally you go to the hospital and have the operation for the fixing of the hip. Then you stay in the hospital a few days and then comes this intermediate period where you have to go either to a nursing home or a rehabilitation facility. At On Lok we take them home. If it is possible we put them in their own home. If not possible we put them into a respite care unit. They are brought to the centers daily for the rehab services.

You are preventing the real breakdown, the emotional and psychological breakdown, so you don't have to start again after they have been institutionalized for 3 or 4 weeks, we start earlier and that break down doesn't occur.

Mr. **Nielson**. Mr. Lewis mentioned it usually requires additional down payment of several thousand, do you require any major——

Ms. ANSAK. No.

Mr. NIELSON. What is the payment per month?

Ms. ANSAK. This past year the cost was $1,408. This includes everything. This includes the acute hospitalization, the nursing home, whatever the person needs. Out of this——

Mr. NIELSON. You take the risk of how much it might cost?

In other words, you take him for a fixed fee regardless of what the medical cost could be?

Ms. ANSAK. Correct. Medicare presently pays us different rates for different people but it is on the average $560. The rest is paid by Medicaid.

If the person does not have Medicaid then the individual has to make that copayment, which presently is up to $1,000. We have some subsidies through United Way.

Mr. NIELSON. Mr. Lewis, I just caught the tail end of your comments.

You made a comment that Mr. Waxman apparently had said that yours was a high-cost alternative, the high-income alternative. How many people on the average have $28,000 and up available to them when they turn 65 or 70—you said the average is 75?

Mr. LEWIS. I am not a good statistican so I am being cautious, because I want you to understand I can become a little anecdotal about some of this. I understand about 50 percent of the population of America over 65 own their own homes and the sale price of a home average is over $80,000.

Assuming that for older people the value of those homes is less, that affords them the opportunity and this is what generally happens in communities like ours is that the individual sells their home and uses a substantial portion of the sale price to enter a community.

Mr. NIELSON. But they can't always get that much money in cash.

Mr. LEWIS. A high percentage of older people own their own homes outright.

Mr. NIELSON. But in selling them don't they have to finance themselves?

They don't get that much downpayment. You work with them?

Mr. LEWIS. Yes.

Mr. NIELSON. If they get $10,000 down payment due you allow them to pay later?

Mr. LEWIS. We do that on rare occasions, but not on any grand scale.

Mr. WYDEN. Would the gentleman yield?

You said you had some low-income people in your program.

What percentage of your people are low income?

Mr. LEWIS. I don't know what you consider low income.

Mr. WYDEN. What do you consider low income?

Mr. LEWIS. I would consider low-income for our community, where someone is making less than $12,000 a year. It would be hard to make it anywhere and get affordable long-term care.

Mr. WYDEN. What percentage then——

Mr. LEWIS. I would say in our communities today, probably, maybe 10 percent to 15 percent have incomes around that level.

Mr. WYDEN. I appreciate the gentleman yielding.

Mr. **Nielson**. One other question. In the notice about the hearing—I apologize for not being here earlier, I was taking care of things that needed to be taken care of—I wondered, there is a tendancy for Medicaid, for people to spend all their assets so they can qualify for Medicaid.

I know my mother visited us in Europe in 1973, had a chance to go to Israel for $400, a beautiful tour. She refused to do that because she wanted to leave something for the kids so when she needed to go into a hospital, she had too much income, partly because she had saved all her life, so the five children took care of all the bills.

Do you have any provision for that if the children of the people can help pay for it themselves, do you have a provision for letting the children pay for it?

Mr. **Lewis**. They don't have to in our communities because we cover those hospital bills.

Mr. **Nielson**. He may not be able to come up with the $28,000. Would you allow the family members to pool their money and take care of that, as well as the monthly cost?

Mr. **Lewis**. We have.

Mr. **Nielson**. How often does that occur?

Mr. **Lewis**. Not too often. Generally our residents are determined to make their own affairs. We do have an aid fund.

The way our communities operate generally, is that it is a group of people who really want to pool the risk of getting older. They do not want to fall back on their children and be a drain to them. That is almost one of the highest goals of people coming into our communities.

Mr. **Nielson**. I guess I take a different attitude. I don't think a parent with children willing to help is being a drain on them. If she has sacrificed for them——

Mr. **Lewis**. I agree; but I am telling you what the older people coming into our communities, what their attitudes are. They do not want to be a burden to their children.

Mr. **Nielson**. Do you think there needs to be some change in the legislation for Medicaid to prevent people from squandering their funds so they can't have funds to take care of themselves.

The incentive now is to get rid of your assets, put the home in somebody elses name so you qualify for Medicaid. Those who refuse to do that end up without much help.

Is that fair?

Mr. **Ebeler**. I don't know that when people spend down to become eligible for Medicaid whether that is the result of squandering their funds. I think think the evidence is that most people who do spend down and have to deplete their resources to become Medicaid eligible have done so because they are going to hospitals and nursing homes. There are specific cases of abuse, but the vast majority are elderly people who have gotten caught in a financial bind. Not many of us can afford a nursing home today.

Mr. **Nielson**. I can give cases where the opposite happened, where families with the same circumstances, one will deliberately waste their assets so they can qualify, the other will hug their assets because they don't want to be dependent.

Is there something we could do about the law to encourage the latter?

Mr. **Ebeler**. It is always appropriate if you can construct legislation that only deals with those individuals who may be consciously squandering assets. The difficulty is that you end up punishing the vast majority of people who are in that situation because they have encountered medical costs that they can't deal with.

It is a very difficult policy for the Congress to deal with.

Mr. **Nielson**. Perhaps I haven't made my point clear. I think that the laws in the various States encourage people to become dependent on Medicaid when they wouldn't need to if they were careful, and there ought to be an incentive to have them be careful so there is less wear and tear on the financial system.

I think we need to start perhaps encouraging that kind of approach.

I yield back, Mr. Chairman.

Mr. **Wyden**. I thank the gentleman.

This reconciliation package, I point out, does include some efforts to try to deal with the matter the gentleman is talking about, of setting up trust funds and that kind of thing, in effect, to get around some of the restrictions on Medicaid. So there is a lot of concern that we get the benefits targeted to those who are most needy.

One general question for the entire panel. Each of you offer up a unique and different kind of approach in trying to meet long-term care needs to older people. Do each of you think that your particular model, starting with social HMOs and going down the table, do you think it could be expanded into a larger system that could be part of a national strategy for long-term care for older people?

Ms. **Ansak**. I think so. We have different models, and different communities, and different needs; and I think we need to have legislation which allows for diversity.

Whether you are going to a rural area or intercity area, I know we are trying at this point, with the help of the Johnson Foundation, to replicate On Lok in other places, perhaps under some different sponsorship. But I think On Lok is not an answer to long-term care in the whole United States.

I think there need to be different models. I think we need to kind of decide what long-term care is. I am not sure we even know that.

Mr. **Lewis**. I share what Marie-Louise Ansak said. I don't see that continuing care is the answer for everyone. I think there is a common thread, though, that runs through our three presentations, and that is that we offer the older person who comes to be involved in our programs a managed health care plan which I think is the key to our success of all three of our systems, and the person who gets into it has the opportunity for getting in this country an extraordinary quality of care which is not otherwise available on any kind of affordable basis.

Mr. **Ebeler**. We are excited about the SHMO concept, but we don't have enough information yet to know whether this is the answer. We see it as a very important contribution to your knowledge base as you develop long-term care policy. I would emphasize something people have said throughout the hearing this morning: the key is not to come up with one model that works nationwide, but to try to identify different options that we can make available to the elderly.

Mr. Wyden. Let me just ask each of you a couple of questions about your particular model. Mr. Ebeler, I am very excited about the promise of the social health maintenance organization. In Portland in my district under the leadership of Mitch Greenlick, we have had a tremendous early success with our social health maintenance organization. It has been a chance to keep a lot of people out of long-term health care facilities, produce real savings to people, and we are very excited about it.

I know you are doing the same kind of work in Minnesota, and I want to ask you a couple of questions so we know a bit more about how your social HMO is working. You include Medicaid patients in your SHMO?

Mr. Ebeler. Yes; we just began marketing to them.

Mr. Wyden. What proportion of your target population is going to be on Medicaid in the near future?

Mr. Ebeler. The target would be 20 percent.

Mr. Wyden. And the SHMO provides an integrated approach to long-term care. We know that, but we would like to know how nursing home benefits fit into the SHMO?

Mr. Ebeler. The long-term nursing home care is included in the long-term care package, subject to the same annual and lifetime limits that the other community-based forms of long-term care services are subject to. If a member needs long-term care, the case management unit would identify that need and could place that person in a nursing home.

I think the key is that nursing home care is but one of a number of delivery alternatives available to the case manager and provider at the time the elderly person becomes disabled.

Mr. Wyden. What happens if the SHMO member needs extended institutional care?

Mr. Ebeler. If the member exceeds the limits of our coverage and is not a Medicaid-eligible person, we try to arrange for financing of that care from other providers in the communities. We have had excellent support from other providers to piece together an even more extensive benefit package.

Mr. Wyden. Tell us a little bit more about how your services are financed. We are interested in whether you needed waivers from Medicare. If so what was the reason given for needing a waiver?

Mr. Ebeler. The services are financed from a variety of sources, which is the nature of a demonstration like this. We get Medicare prepayment for the Medicare enrollees, Medicaid payments from the State agency. We collect the $29.50 monthly premium from the Medicare eligibles. We have gotten excellent foundation support for the planning and pre-operational phases of the project. The sponsors finance the initial operating losses subject to upper limits with risk sharing from the Medicare program. Finally, other agencies in the community help to finance some of the care when the coverage limits in the program are exceeded.

We needed a number of waivers to put this package together, and it took a long time to get them. This subcommittee was very helpful in getting us those waivers. They were held up for 10 months at OMB, and finally, in the Deficit Reduction Act, the Congress mandated that the Department of Health and Human Services grant those waivers so that we could become operational last January.

Mr. **Wyden**. This subcommittee has been red hot in its anger about the waiver issue because it seems to me that exactly what the President said we ought to be doing is trying out experimental approaches, new approaches. Go slow. We are starting huge new entitlement programs, but try new things to try to determine what works, programs like yours and Mitch Greenlick's and others.

Chairman Waxman has been able to put together an approach using things that Senator Bradley and I introduced on a bill. Chairman Waxman took a variety of these. You need to let us know what happens in the years ahead. I think you will try other innovative approaches and ideas. We want to make sure we have a waiver program that works for trying out new experiments and not one that is ensnarled in red tape in bureaucracy.

We thank you. You are missed here on the subcommittee. Minnesota's gain is our loss. Thank you.

A couple questions for you, Mr. Lewis. Is there any interest among organizations like yours in designing programs that could serve a larger number of the poor population? We are pleased that you have got a 10- to 15-percent number right now. Is there any likelihood that your kind of program is going to be available to larger numbers of the poor?

Mr. **Lewis**. Two of the different organizations that I am involved in, one is a subsidiary of our operation, we are trying to design the lowest possible cost community contained within a campus setting such as our own, and we have been spending the last 3 or 4 months examining each component that is a part of our operation and seeing how we could do it—what will be the lowest cost for each component and trying to put them together with the essential health care plan and health care program being the one we are least willing to give up dollars on, because we think that that is where we must not pinch.

But we expect to finish that particular study by the end of this year, and we hope that we would be able to extend this program to a wider group. I am not terribly optimistic about reaching down to lower middle-income people with our concept without additional support from the Government.

Mr. **Wyden**. You don't think there is a real likelihood, say, that there will be a target on the group that we were talking about? The $12,000, $15,000, $16,000, that is not in the future?

Mr. **Lewis**. We are trying to serve that group. I think there is a real possibility we could, but I will also anticipate considerable market resistance because we would be asking people who would have relatively few dollars and had spent their life earning those dollars to pay out for a health care plan—they are going to be getting a lot of other services, their home and a lot of other social services that go with living in a community, but we are asking them to pay that out in a lump sum at the outset, and that is a hard concept for someone who does not have a lot of dollars to grab hold of.

Mr. **Wyden**. They are very interested in knowing about any kind of financing arrangement that is going to work. It is not as if they are going to stay away if there is a supply.

Mr. **Lewis**. We have been trying to market, this is another program we are working on that we call a continuing care plan. This is where we are trying to, very similar to the two programs we have been talking about, delivering services to a group of people in a much larger defined geographic area, but not a single campus. Again, we have run into constantly this number of 60 to 70 to 80 percent of the population believing that long-term care is going to be covered by Medicare and, therefore, why should I bother? That is a constant barrier that you hit.

Mr. **Wyden**. Is nursing home service covered through your monthly fee schedule?

Mr. **Lewis**. Yes. The people in our skilled nursing care center, where they are getting that highest level of care, pay the basic monthly rate of $923.

Mr. **Wyden**. Maybe it would be helpful for me to understand how your various kinds of financing arrangements interact. Medicare or private health insurance covers the resident's acute health care needs?

Mr. **Lewis**. That is correct. Not all of it, because the deductible is covered by us out of the moneys that we collect from the residents.

Mr. **Wyden**. Which is the monthly fee schedule?

Mr. **Lewis**. That is correct, and the entrance fee.

Mr. **Wyden**. So you have got an entrance fee, a monthly fee schedule, and then Medicare or private insurance?

Mr. **Lewis**. Yes; that is correct. Medicare and private insurance, though, the total that we receive in any one year, we always keep within manageable reach should the program never be not available to us for some reason that we could survive without it, and our level—we probably are drawing somewhere in the neighborhood of $400,000 or $500,000 for our communities from the Medicare system. We could—by raising rates a very modest sum, we could cover that if we ever had to.

Mr. **Wyden**. Are your facilities associated with the Quaker Church, Mr. Lewis?

Mr. **Lewis**. All the members of our board of directors are members of the Religious Society of Friends, Quakers.

Mr. **Wyden**. One of the things we are very concerned about, because it has been a trademark of every area where older people have been in need of private services, is that there is always, at the outset in particular, a small minority who try to take advantage. It has happened in virtually every area, for example the immediate gap policies for filling in the gaps for Medicare.

Do you think that there is any danger of fraud and abuse and marketing kind of high-pitch sales techniques?

Mr. **Lewis**. There has been considerable danger in my field for the past 7 or 8 years. There have been a lot of abuses. Those abuses have been rather noisy, and most people hear about them, but the bulk of the industry is sound. Like anything else, there are people that try to take advantage of it. I don't think they come in with the idea of failing, but we have had failures that have been painful for bondholders and investors and residents.

Mr. **Wyden**. I would say if the Government is today more in this area and would there be good, solid consumer protection?

Mr. **Lewis**. In Pennsylvania, we have legislation in place which would prevent further things like that happening in our State. The American Association of Homes for the Aging is now developing an accreditation program for our industry which will, with State legislation, will I think prevent that kind of thing in the future.

Mr. **Wyden**. The other thing we were interested in knowing, Mr. Lewis, is what would happen when a resident dies in terms of the assets. How is this handled?

Mr. **Lewis**. If a resident dies within the first year, and in our community, and this will differ from place to place, in our community 50 percent of the entrance fee would be remitted to that person's estate. Otherwise after that——

Mr. **Nielson**. Would the gentleman yield? After what period of time?

Mr. **Lewis**. After 1 year.

Mr. **Nielson**. Just one time?

Mr. **Lewis**. That is just one time. If a resident dies within the first year. If they chose to leave, we give them all their entrance fee back in the first 3 months. Thereafter, if they choose to leave, it is amortized on the basis of 2 percent per month, so in 50 months, if they choose to leave, they would have lost their entrance fee. Anyone who dies after the first year, the entrance fee is forfeited and is part of the program, part of the insurance.

If I could—it is very hard for a lot of people to grasp that initially. I could sometimes explain it by using the reverse, that it is the same kind of thing that if you bought a life insurance policy and you died in the first 6 months and the life insurance company said, "We didn't expect you to do that, so, therefore, we would like not to pay on the policy." It is the same principle involved, just in reverse.

Mr. **Wyden**. Did the gentleman want to ask any more questions?

Mr. **Nielson**. I wanted to ask Mr. Ebeler, do you believe that your proposal would fit—I know the chairman asked this question, but I wasn't satisifed with your answer—do you believe your proposal would work in other parts of the country?

Mr. **Ebeler**. It appears to be working in the other three sites. I don't think we know enough to know whether one would want to expand it at this point. I am excited about it, but I think from your perspective, you should wait and see. The Health Care Financing Administration is funding this as a demonstration and it is going to attempt to be able to answer that question for you in 2 or 3 years.

Mr. **Nielson**. The basic difference between yours and the other two seems to be that they are for certain fee or requirements, then they cover the costs, whatever they might happen to be, whereas yours varies with whatever you come up with. That is a basic difference.

Have you considered going to something like a guaranteed type care for certain risk involved on your part, in other words, to a DRG approach that Mrs. Ansak talked about, have you considered that?

Mr. Ebeler. We have considered a variety of those things. We are at this point committed to fulfilling this demonstration because of the variety of commitments we have made to the Federal Government and our need to complete the demonstration protocol.

Again, I think there are a variety of options. The On Lok program has a history of success that is phenomenal, and I think all those options need to be evaluated.

Mr. Nielson. Apparently the DRG type program is set sufficiently liberal that On Lok is able to come out of it all right on a financially sound basis and still provide care that is remarkable in the sense that they have less hospitalization, shorter hospitalization. Wouldn't the fact that they knew their bills were going to be taken care of give them sort of a peace of mind and actually keep them healthier? Do you think some aspect of that helps her program?

Mr. Ebeler. I am sure that helps her program. We offer a great deal of that coverage. If you are enrolled in Senior's Plus, more long-term benefits are covered than in traditional plans. I think it is one of the important advantages of any of these approaches.

Mr. Nielson. In the last Congress, we discussed health insurance, the person who is unemployed through no fault of his own, and the first thing that happens, he has to pay the individual rate rather than the group rate. Many of them drop the insurance to save money, and the fact that they are without insurance increases their possibility of getting sick.

I would think the approach of Mrs. Ansak and Mr. Lewis would have people in a better frame of mind. They know they are taken care of. I think that would strengthen your program, if you could borrow from their taking the risk and saying "We will cover the risk", set the fees high enough to cover the risk or get good funding. I bet you would have a healthier, happier group. I just recommend that.

Now in the case of Mr. Lewis, maybe they can't all afford the entry fee. I still feel that you are cutting out a good many people that need to be served although I commend you for what you do. I commend all three of you for being here today. Thank you very much.

Mr. Wyden. I thank the gentleman.

Just a couple questions for you, Mrs. Ansak. We understand that On Lok serves only the frail elderly, those who are essentially most vulnerable to institutionalization. We would be interested in knowing whether the program is also workable for those who are a little less vulnerable but still in need of some type of long-term care assistance. I guess the question that comes to mind is, is that doable and could it be cost effective if you did both?

Ms. Ansak. I think so. I think actually, you know, we are starting at the other end. The SHMO starts with the people who are better off, and we could expand into that group. For x number of reasons we didn't want to do this, partly politically in the community and partly because when you deal with a frail elderly, if the program gets too large, you then have a factory. We have 300 participants, and I think that is all we can deal with basically.

I think one could expand the idea and perhaps set up something concurrently to serve the less frail. I think one could ultimately save money, no question, if you can prevent, because we are saving money with the very, very frail. I think if you would have a similar system for those who are less frail, I definitely think we could save some money.

Mr. **Wyden**. We are also interested in how we can stimulate more programs like yours around the country.

Ms. **Ansak**. We will come back to you shortly. We are trying, with the help of the Robert Wood Johnson Foundation to stimulate the replication of On Lok in other areas, particularly in Albuquerque, NM there is a group interested, one in Denver, one in Boston and one in New York. It will be very interesting to see whether the program can be replicated. We will need waivers, so we will be back before the committee, I suppose.

Mr. **Wyden**. We are always happy to see you and your associates. If my colleague doesn't have any further questions——

Mr. **Nielson**. Mr. Chairman, I think I would like to ask the same question of Mr. Lewis, do you think you could expand your program to the less frail—she says you start with the choice ones, could you move more to the middle and more to the lower-income group and still be successful?

Mr. **Lewis**. We think we are serving the middle-income group, but we are trying to reach a lower income group. Give me another year, year and a half, and I will tell you how it goes.

Mr. **Nielson**. Thank you.

Mr. **Wyden**. We thank all three of you. We started this hearing about 3½ hours ago, or something along those lines. I started off by saying that I have recently seen the movie "Cocoon" and thought about those spirited seniors who took off to the other planet where they never had to worry about bill collectors and had the promise of perpetual life.

You and our other witnesses have made it clear to us earthlings that it is not that simple. You have given us innovative ideas and, more importantly, I think we have been able to build a record which I know Chairman Waxman wants to use to develop a national strategy for delivering long-term care services in this country.

What we have been interested in is not an abstract sort of session where we gather information and it is filed away in some kind of report. Our chairman wants to develop a solid long-term care strategy that includes a variety of different pieces. The Government very definitely has a role to play particularly in serving the low income and those who cannot pay for their own care. We think there is an opportunity for the private sector to play a role and have moved toward that in our reconciliation package.

I imagine there will be a variety of approachings ranging from SHMO's to the life care kind of arrangement, or continuing care as it is called, to the very fine work of On Lok which we wish to duplicate elsewhere as well. So keep us supplied with fresh innovative suggestions that we can consider for this national strategy. We must go after what I think is a great unmet need in this country for our older people, long-term care. Unless you have any further comments, we will excuse you.

The subcommittee is adjourned.

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FINANCING AND DELIVERY OF LONG-TERM CARE SERVICES FOR THE ELDERLY

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October 17, 1985

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EXECUTIVE SUMMARY

The projected growth of the elderly population, combined with large and increasing Federal and other public expenditures for long-term care services, and especially nursing home services, has generated substantial interest in altering the way in which long-term care services are financed and delivered. In the past, legislative interest has focused in part on coordination of existing Federal programs financing long-term care in order to offer more consistent and adequate protection for the potentially catastrophic expenditures the elderly can incur as the result of chronic illness. In addition, policy-makers have also sought ways to expand community-based services to correct what some perceive to be a bias in the current system in financing institutional long-term care. This report provides an overview of selected policy issues on long-term care financing, including information on characteristics of the elderly and their need for and utilization of long-term care services, and a review of public sector programs and private sector approaches to financing long-term care services.

The phrase "long-term care" refers to a wide array of medical, social, personal, and supportive services needed by individuals who have lost some capacity for self-care due to chronic illness or physical or mental conditions which result in both functional impairment and physical dependence on others for an extended period of time. Major subgroups of individuals needing long-term care include the elderly and non-elderly disabled, the developmentally disabled (primarily the mentally retarded) and the mentally ill. This report focuses principally on long-term care services required by the elderly, generally those persons 65 years and older. Elderly persons, by virtue of their high risk of chronic illness that results in disability and functional impairment, are the primary recipients of long-term care in this country.

The range of chronic illnesses and conditions resulting in the need for supportive long-term care services is extensive. Unlike acute illnesses, which occur suddenly and are usually resolved in a relatively short period of time, chronic conditions are of an extended duration and may be difficult to treat medically except to maintain the status quo of the patient. Although chronic conditions occur in individuals of all ages, their incidence, especially as they result in disability, increases with age. These conditions may include heart disease, strokes, arthritis, and vision and hearing imapriments. Dementia, the chronic, often progressive loss of intellectual function, is also a major cause of disability in the elderly. At least half and perhaps as many as 70 percent of patients with dementia have Alzheimer's disease, a chronic, progressive, primary neurologic degeneration of unknown cause, which increases in prevalence with advancing age and for which there is currently no effective treatment.

Long-term care services include a wide variety of health and social services provided in an institution, in the community, or in the home. Services range from medical and therapeutic services for the treatment and management of chronic illness provided by skilled personnel to assistance with basic activities of daily living, such as housekeeping and personal care services, provided by family members, nurses, and social workers. By far, the majority of long-term care services are provided by family members.

Based on the projected growth of the elderly population and current utilization patterns of institutional and community long-term care services, major increases in the demand for long-term care can be anticipated for the future. Today approximately 1.2 million elderly persons are residents of nursing homes.

This is about five percent of the total elderly population. With current utilization, the National Center for Health Statistics has estimated that the number of elderly nursing home residents will increase by 58 percent from 1978 to 2003 when constant mortality is assumed and by over 115 percent when declining mortality is assumed. In addition, for every person 65 years of age and over residing in a nursing home, there are twice as many persons living in the community requiring the various kinds of care provided in an institution.

At least 80 Federal programs assist persons with long-term care problems, either directly or indirectly through cash assistance, in-kind transfers, or the provision of goods and services. Among these 80 programs, five are generally considered to be the major programs of Federal support for long-term care: Medicaid, Medicare, the Social Services Block Grant, the Older Americans Act, and the Supplemental Security Income program. No one program, however, has been designed to support a full range of long-term care services on a systematic basis.

For example, the Medicare program is intended to address the acute medical care needs of the aged and disabled. To the extent that is provides coverage for certain long-term care services, it does so with the intent of reducing the need for more intensive and expensive acute care serivces. The program was not designed to respond specifically to the chronic care needs of the elderly, for instance those with Alzheimer's disease, over a sustained period of time.

The Medicaid program on the other hand, does support long-term services, principally nursing home care, but only for certain low-income people or for persons who have depleted their income and assets. Many persons become eligible for Medicaid's nursing home benefit only after they have depleted their income and assets on sizable out-of-pocket expenditures for long-term care.

The Social Services Block Grant program, by way of contrast, is generally limited to the provision of community-based social services selected and defined by the State. This program may cover medical care only when it is integral but subordinate to the provision of a social service. Funding under title III of the Older Americans Act is used for the development of a service delivery system for older persons, focusing on social and nutritional services. The Supplemental Security Income program provides cash assistance to needy aged, blind, and disabled individuals.

In addition, varying eligibility requirements, service benefits, service definitions, and reimbursement policies among these five major Federal programs supporting long-term care have resulted in a fragmented and uncoordinated long-term care policy at the Federal level. This lack of coordination among Federal programs has also presented major implementation challenges to the States, especially where certain of these programs delegate administrative responsibility to State governments.

The following chart summarizes some of the major differences among Federal programs which support institutional and community-based care.

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Major Federal Programs Supporting Long-Term Care Services: Services Covered, Eligibility, and Administering Agency

			Administering agency	
Program	Services covered	Eligibility	Federal	State
Medicaid/ Title XIX of the Social Security Act	Skilled nursing facility a/ Intermediate care facility b/ Home health c/ Adult day care b/	Aged, blind, disabled persons receiving cash assistance under SSI; others receiving cash assistance under AFDC. At State option, persons whose income exceeds standards for cash assistance under SSI/AFDC, i.e., the "medically needy."	Health Care Financing Administration/HHS	State Medicaid agency
	2176 "waiver" services, e.g., case management, homemaker, personal care, adult day care, habilitation, respite, and other services at State option. d/	Aged, blind, disabled, or mentally ill Medicaid eligibles (including children) living in the community who would require nursing home level care. At State option, persons living in the community with higher income than normally allowed under a State Medicaid plan.		In some cases, the 2176 "waiver" program may be administered by another agency, e.g., State agency on aging.
Medicare/ Title XVIII of the Social Security Act	100 days of skilled nursing facility care Home health Hospice	Generally Social Security status. Persons 65 years and over; persons under 65 years entitled to Federal disability benefits; and certain persons with end-stage renal disease.	Health Care Financing Administration/HHS	N/A
Social Services Block Grant/Title XX of the Social Security Act	Various social services as defined by the State, including homemaker, home health aide, personal care, home-delivered meals	No Federal requirements. States may require means tests.	Office of Human Development Services/HHS	State social services/human resources agency. In some cases other State agencies may

Major Federal Programs Supporting Long-Term Care Services: Services Covered, Eligibility, and Administering Agency--Continued

Program	Services covered	Eligibility	Administering agency	
			Federal	State
Social Services Block Grant/Title XX of the Social Security Act (cont'd)				administer a portion of title XX funds for certain groups, e.g., State agency on aging.
Older Americans Act/ Title III	Variety of social services as determined by State and area agencies on aging, with priority on in-home services. Also case management, day care, protective services. Separate appropriation for home-delivered meals.	Persons 60 years and over. No means tests, but services are to be targeted on those with social or economic need.	Administration on Aging/Office of Human Development Services/ HHS	State agency on aging
Supplemental Security Income/ Title XVI of the Social Security Act	Federal income support. Maximum Federal payment for person with no income is $325 per individual and $488 per couple in 1985. Supplemental payment for non-medical housing and/or in-home services, as determined by State.	Aged, blind, disabled persons who meet Federally established income and resources requirements. States may make payments to other State-defined eligibility groups.	Social Security Administration/ HHS	State supplemental payment program may be State or Federally administered.

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a/ Required for individuals over age 21.

b/ At option of State.

c/ Required for individuals entitled to skilled nuring home care.

d/ May be offered under a waiver of Medicaid State plan requirements, if requested by the State and approved by HHS. May include waiver of Medicaid eligibility requirements and stipulation that services be offered on a statewide basis.

Policymakers have also been concerned about striking the right balance between nursing home care services and home and community-based long-term care services. By far the largest portion of public expenditures for long-term care is for nursing home care, with the Medicaid program accounting for 43 percent of total national spending for nursing home care. Other programs, such as the Social Services Block Grant and the Older Americans Act, while providing a range of community-based long term care services, have limited ability to provide a balance to the enormous institutional support provided through the Medicaid program. Long-term care reform in the past, therefore, has included efforts to reduce inappropriate institutionalization of the chronically ill by creating programs to assure that those referred for institutional care actually need such care and by increasing the availability of community-based care services, such as home care and adult day care services.

Various Federal research and demonstration projects have attempted to test new ways of providing and coordinating long-term care services. These have included projects to develop case management and assessment procedures to better target services to those most at risk of institutionalization, and to create new community-based service options. Some of these projects have led to the initiation of the National Long-Term Channeling Demonstration program by the Department of Health and Human Services (DHHS). The Channeling Demonstration was designed to test whether a carefully managed approach to the provision of community-based long-term care services to a frail elderly population living outside institutions could help control overall long-term care costs while maintaining or improving the well-being of clients. Another major research and demonstration initiative of DHHS currently underway is the social/health maintenance organization (S/HMO). This project builds upon and extends the health maintenance organization model, where health care services are offered to a defined population on a pre-paid capitation basis. The S/HMO provides not only conventional health care services to a group of elderly persons but also provides a range of long-term care services including nursing home care, home health, and homemaker services. Among the questions to be addressed by this demonstration are whether a consolidated pre-paid system of acute and long-term care can produce greater savings than conventional HMOs already serving Medicare beneficiaries, and whether the long-term care services offered through the program will reduce nursing home admissions and the number of persons who become eligible for Medicaid's nursing home benefit after they have depleted their income and assets on expenditures for long-term care.

Uncertainty about the potential costs of expanded community-based care, and intervening concern about budget deficits and increasing expenditures under entitlement programs which currently finance long-term care, have shifted the focus of the long-term care debate to consideration of private sector initiatives which might relieve fiscal pressures on public programs and which, at the same time, might improve the elderly's ability to finance long-term care. Some of the private sector options advanced as feasible alternatives for financing long-term care include private health insurance, life care communities, and home equity conversion. Not discussed in this report are other options often suggested as alternative financing mechanisms for long-term care, including the various tax code amendments proposed to encourage families to continue providing long-term care services.

Currently, relatively few insurance companies (studies indicate 16 to 25) write long-term care insurance policies which are substantially more comprehensive than standard policies supplementing Medicare coverage. It is estimated that only about 50,000 elderly persons are presently insured under such plans. A number of barriers have been cited as impediments to the development of meaningful long-term care insurance policies, such as the potential for adverse selection (where only persons more likely to need long-term care buy insurance) and induced demand (where individuals decide to use more services because they have insurance and/or will shift from non-paid providers, such as family members, to paid providers of care). Recent research, however, suggests that some of these barriers may be resolved in a number of ways, including expanding the pool of the insured by encouraging people to buy at younger ages.

Life care communities, also called continuing care retirement communities, are living arrangements available to a limited but potentially growing number of older persons. Such communities are established to provide housing, meals, housekeeping, and certain long-term care services, as necessary, to older persons for the duration of their lives. Older persons enter into a contractual agreement which sets forth the services to be received by the resident in exchange for financial payments, including an entrance fee and monthly payments. The number of existing life care communities is estimated to range from 300 to 600, but this number is expected to more than double in this decade. Supporters of this concept indicate that a life care contract provides financial protection against the future costs of long-term care and offers a protective living arrangement for persons whose needs will increase over time. However, because of the substantial fees required for entrance, some analysts believe this option may be available to only a limited proportion of the elderly population.

Home equity conversion contracts, in which older persons use the equity in their homes to finance certain expenses, have also been advanced as a means to finance certain long-term care services. While substantial numbers of elderly persons have accumulated equity in their homes, to date only a very limited number (estimates of about 300-400 at most) of home equity conversion contracts have been negotiated.

Observers have pointed out that the economic status of future generations of the elderly may improve to the extent that they will be able to finance, through risk pooling arrangements, at least a portion of their long-term care expenses themselves, without resorting to the impoverishment currently required under Medicaid to qualify for that program's nursing home benefit. In addition, others have noted that public programs will simply not be able to support expanded long-term care services in the future as the ratio of workers to retirees declines and as the number of the very oldest segment of the population increases. For the time being, however, these options appear to provide only limited opportunities for alternative financing schemes for long-term care. In addition, they seem to have only limited applicability for the large numbers of elderly who are poor or may be poor in the future.

FINANCING LONG-TERM CARE SERVICES FOR THE ELDERLY

I. INTRODUCTION

The phrase "long-term care" refers to a wide array of medical, social, personal, and supportive services needed by individuals who have lost some capacity for self-care due to chronic illness or physical or mental conditions which result in both functional impairment and physical dependence on others for an extended period of time. Major subgroups of individuals needing long-term care include the elderly and non-elderly disabled, the developmentally disabled (primarily the mentally retarded) and the mentally ill. This report focuses principally on long-term care services required by the elderly. Elderly persons, by virtue of their high risk of chronic illness that results in disability and functional impairment, are the primary recipients of long-term care in this country. 1/

The range of chronic illnesses and conditions resulting in the need for supportive long-term care services is extensive. Unlike acute illnesses, which occur suddenly and are usually resolved in a relatively short period of time, chronic conditions are of an extended duration and may be difficult to treat medically except to maintain the status quo of the patient. Although chronic conditions occur in individuals of all ages, their incidence, especially as they result in disability, increases with age. 2/ These conditions may include heart

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1/ Doty, Pamela, Korbin Liu and Joshua Wiener. An Overview of Long-Term Care. Health Care Financing Review, v. 6, no. 3, spring 1985. p. 69.

2/ Rice, Dorothy and Carroll Estes. Health of the Elderly: Policy Issues and Challenges. Health Affairs, v. 3, no. 4, winter 1984. p. 29.

disease, strokes, arthritis, and vision and hearing impairments. Dementia, the chronic, often progressive loss of intellectual function, is also a major cause of disability in the elderly. 3/ At least half and perhaps as many as 70 percent of patients with dementia have Alzheimer's disease, a chronic progressive primary neurologic degeneration of unknown cause, which increases in prevalence with advancing age and for which there is currently no effective treatment. 4/

The presence of a chronic illness or condition alone does not necessarily result in a need for long-term care. For many individuals, their illness or condition does not result in a functional impairment or dependence and they are able to go about their daily routines without major hindrance or need for assistance. 5/ It is when the illness or condition results in a functional or activity limitation that long-term care services may be required. Limitations can vary in severity and prevalence. For example, a chronic condition may result in dependence in certain basic self-care functions such as bathing, dressing, eating, toileting, and/or mobility from one place to another. These are referred to as limitations in "activities of daily living" (ADLs). A second set of measures reflecting lower levels of disability in the performance of a daily routine are often referred to as limitations in "instrumental activities of daily living" (IADLs). 6/ These include such functions as shopping, cooking, cleaning, managing money, and taking medicine. For example, certain individuals may not have

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3/ Rowe, John. Health Care of the Elderly. New England Journal of Medicine, v. 312, no. 13, Mar. 28, 1985. p. 831.

4/ Rowe, p. 831.

5/ Long Term Care: Background and Future Directions. Health Care Financing Administration, Department of Health and Human Services, Jan. 1981, HCFA 81-20047. p. 4.

6/ Liu, Korbin and Kenneth Manton. Disability and Long-Term Care. A paper presented at the Methodologies of Forecasting Life and Active Life Expectancy Workshop. Bethesda, Maryland, June 25-26, 1985.

limitations in basic self-care functions, but may not be able to clean or shop without some kind of assistance. Other individuals may suffer from a chronic condition or multiple conditions resulting in limitations in both ADLs and IADLs and therefore require a number of specific long-term care services.

Long-term care services include a wide variety of health and social services provided in an institution, in the community, or in the home. Services range from medical and therapeutic services for the treatment and management of chronic illnesses and conditions to assistance with basic living services associated with shelter and meals, such as housekeeping and shopping, to personal care assistance, such as bathing, grooming, and toileting. Such services are generally provided by nurses, social workers, therapists, and a wide variety of unskilled personnel, such as homemakers, nurses aides, and volunteers. Community-based services can be provided formally by agencies or organizations that are paid for their services, or informally by family or friends who offer assistance without compensation. By far, the great majority of long-term care is provided informally by family or friends.

The projected growth of the elderly population, combined with large and increasing Federal and other public expenditures for long-term care services, and especially nursing home services, has generated substantial legislative interest in altering the way in which long-term care services are financed. This report discusses the financing of long-term care services, and especially the extent to which various Federal programs cover and fund these services. It also describes various proposals that have been advanced as alternative private financing schemes for long-term care.

II. SELECTED CHARACTERISTICS OF THE ELDERLY AND MEASURING THEIR NEED FOR LONG-TERM CARE

The need for long-term care services in the future will depend on a number of factors, including demographic changes in the Nation's population, economic conditions which affect an individual's ability to pay for services, levels of disability, and medical advances in the prevention and treatment of chronic conditions. Estimating the dimension of the need for long-term care is a difficult but critical task for policymakers. It is critical since large and increasing amounts of public dollars finance long-term care services. It is difficult because the impact of certain of these factors cannot be predicted with certainty. For example, medical advances may result in the prevention of certain chronic conditions, or simply in incremental improvements in their management. Medical and scientific advances can also lead to reductions in general mortality which would result in increases in the size of the potential long-term care population. This section provides information about certain demographic and income characteristics of the elderly population.

A. Growth of the Elderly Population

The aging of the Nation's population has dramatic implications for projections of need for long-term care services. The elderly population has grown much more rapidly in this century than has the remainder of the population. As table 1 shows, from 1900 to 1950, the total population doubled in size while the population aged 65 and over increased by four times; from 1950 to 1980, when the total population increased by 50 percent, the aged population doubled in size, to 25.5 million. Between 1980 and the year 2020, the total population is projected to increase by slightly more than 30 percent, while the elderly population is projected to more than double again. By 2020, the projected elderly population will be 51.4 million, 17.3 percent of the total population.

TABLE 1. Size of the Elderly Population, 1900 to 2020
(in thousands)

Year	Total U.S. population	65+		85+		Aged support ratio*
		No.	%	No.	%	
1900	76,303	3,084	4.0	123	0.2	7.6
1950	150,697	12,270	8.1	577	0.4	13.7
1980	226,505	25,544	11.3	2,240	1.0	18.6
2000	267,955	34,921	13.0	4,926	1.8	21.6
2020	296,597	51,422	17.3	7,081	2.4	29.3

* Ratio of 65+ plus population to working age population, 19-64 years.

Source: U.S. Department of Commerce. Bureau of the Census. Decennial Censuses of Population 1900-1980 and Projections of the Population of the United States by Age, Sex, and Race: 1983 to 2080 (Advance Report). Current Population Reports, Series P-25. No. 952. May 1984. Projections are middle series.

As a result of the rapid increase in the elderly population, their proportion of the population increased from 4.0 percent in 1900 to 11.3 percent in 1980; this is expected to increase to 13.0 percent by 2000. At the same time, the number of elderly in comparison to the number of persons in the working age population (persons aged 19-64) has increased substantially. The aged support ratio (that is, the ratio of the 65+ population to the working age population 19-64 years) increased from 7.6 in 1900 to 18.6 in 1980 and is expected to increase to 29.3 by 2020.

Despite the overall growth in the 65 plus group, the most critical demographic factor with implications for the future of long-term care service utilization is the startling pace of increase in the oldest segment of society. The "old-old," persons 85 and over, are currently the fastest growing age group in the U.S. population. This group represented only 0.2 percent of the total population in 1900, but increased to 1.0 percent in 1980; by 2020, they are projected to be 2.4 percent of the population, and nearly 14 percent of the elderly population (up from about 9 percent in 1980).

B. Economic Characteristics of the Elderly

1. Income

In 1984, the median income of families headed by persons 65 or older was $18,215; the median income of an unrelated individual in the same age group was $7,296. (There were 9.8 million such families and 7.3 million such unrelated individuals.) 7/ This compares to $24,433 for all families and $11,204 for all unrelated individuals. Data from the 1980 Census of Population and Housing show that the cash income of the elderly is lower in each older age group. 8/ Married couples with a head aged 65-69 had median incomes of $18,400, compared to $11,200 for those 85 and over. Men aged 65 to 69 and living alone had median incomes of $8,200, while those 85 and over had incomes of $6,000; the comparable figures for women living along were $6,800 and $5,200, respectively. In 1983, the after-tax, disposable income of elderly households, adjusted for family size,

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7/ U.S. Bureau of the Census. Current Population Reports. Series P-60, no. 149. Money Income and Poverty Status of Families and Persons in the United States: 1984 (Advance Data from the March 1985 Current Population Survey). U.S. Govt. Print. Off., Washington, D.C., 1985. p. 12.

8/ U.S. Bureau of the Census. 1980 Census of Population and Housing. Public Use Microdata Sample. Special tabulations.

was less than that of households with heads aged 50 to 64, but higher than all other households. 9/ Among the younger old, and particularly among those who will become old in the next decade, pension coverage is higher than was the case for the old-old. At the same time, early retirement is an increasingly common phenomenon.

2. Poverty Rates

The poverty rates for the elderly have shown a dramatic decline over the last 25 years. In 1959, the poverty rate was 35.2 percent for the elderly and by 1984 the rate had fallen to 12.4 percent, the lowest rate ever recorded for that group. In addition, from 1982 to 1984, the poverty rates among the elderly population in general have been lower than those of the rest of the population. In 1984, 12.4 percent of those 65 and over were poor in comparison to 14.4 percent of the entire population. (In 1984, the estimated poverty threshold for persons 65 years and over was $4,979, and for two person families whose head was 65 years and over, it was $6,282.) These aggregate figures, however, mask important differences within both the elderly and the remainder of the population. The poverty rate among other adults (persons 22 to 64), for example, was 11.1 percent in 1984; the rate for the entire population is inflated by the very high rates of poverty among children. 10/

There are specific groups among the elderly that are at substantially greater risk of poverty. Poverty rates increase sharply with age; in 1980, the

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9/ U.S. Bureau of the Census. Current Population Reports. Series P-23, no. 143. After-Tax Money Income Estimates of Households: 1983. U.S. Govt. Print. Off., Washington, D.C., 1985. p. 31.

10/ Money Income and Poverty Status of Families and Persons in the United States: 1984. p. 26 and p. 31.

rates varied from 13.6 percent among those 65 to 69 to 27.3 percent among those 85 and over. Women have rates that are two to three times as high as men; women 85 and over had poverty rates of 34.1 percent compared to 17.2 percent among men. Finally, elderly who live alone have much higher rates than do persons living with a spouse or with children. People aged 85 and over living alone in 1980 had a poverty rate of 36.8 percent, in contrast to a rate of 12.4 percent among those living with a spouse. 11/ In all cases, the poverty rates are much lower among the young-old (persons 65-74 years of age).

3. Assets

In 1979, the assets of the elderly, including equity in their homes and automobiles as well as other financial assets, also varied by age group. Households with heads aged 65 to 69 on average had more assets ($89,200) than households with heads 70 and over ($73,800). The age group that will become elderly in the next decade, those 55 to 64, had a higher level of assets ($110,200) than their immediate seniors, and also a higher level than younger age groups ($77,600 for those 45 to 54 and $68,500 for those 35 to 44). 12/ Beginning with those aged 55 to 64, an increasing share of assets are in the form of home equity. This ranges from just under 40 percent of assets among those aged 55 to 64 to nearly 50 percent among those 70 and over.

11/ The 1980 Census of Population and Housing. Ibid.

12/ Torrey, Barbara Boyle. The Visible Costs of the Invisible Aged: The Fiscal Implications of the Growth in the Very Old. A paper presented at the annual meeting of the American Association for the Advancement of Science, May 1984.

4. Future Resources

A number of sources indicate that in the future, the new elderly will have increasingly higher incomes and assets. These predictions may have implications for the ability of the elderly to finance long-term care. Median income among the elderly as a whole has been projected to rise (controlling for inflation) from 10 to 20 percent from 1980 to 1995 (assuming 1.0 to 1.5 percent average annual growth in income among the general population). 13/ Under the same growth assumptions, income among persons 55 to 64 is projected to increase from between 15 and 20 percent in the same period. Asset levels are even more difficult to project, but because of the improved historical personal economic experiences of the future aged who have lived through the post-World War II prosperity, some anticipate that their levels of resources will be considerably greater than past generations of elderly. 14/

Although the relative well-being (measured with income and assets) of the future elderly may on average be greater than that of recent generations of elderly, there will also continue to be large differences among the various groups of the elderly. Some of the differences will be the same as those described above, based either on lifetime differences of individuals or on sudden or gradual changes in family status or available sources of income and assets. Even if poverty rates are substantially lower than they currently are, there may be more poor elderly than there are now, because of the increasing numbers of elderly people. For example, if poverty rates among the elderly drop 20 percent by the

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13/ U.S. Bureau of the Census. Current Population Reports. Series P-60, no. 122. Illustrative Projections of Money Income Size Distributions for Households: 1980 to 1995. U.S. Govt. Print. Off., Washington, D.C., 1980. Series C. 1.0 and 1.5 percent growth in household income.

14/ Etheredge, Lynn. An Aging Society and the Federal Deficit. Milbank Memorial Fund Quarterly/Health and Society, v. 62, no. 4, 1984. p. 527.

year 2000, to 10.0 percent (from the current 12.4 percent), there would still be 3.5 million poor elderly--compared to 3.3 million in 1984. If poverty rates were to remain constant, there would be 4.3 million poor elderly in 2000. These factors will continue to exert pressure on public sector long-term care programs.

C. Utilization of Institutional and Community-based Long-Term Care Services

Based on the projected growth of the elderly population and current utilization patterns of institutional and community long-term care services, major increases in the demand for long-term care can be anticipated for the future. Today approximately 1.2 million elderly persons are residents of nursing homes. This is about five percent of the total elderly population. With current utilization, the National Center for Health Statistics has estimated that the number of elderly nursing home residents will increase by 50 percent from 1978 to 2003 when constant mortality is assumed and by over 115 percent when declining mortality is assumed. 15/

The rates of nursing home utilization are most dramatic when broken down by age group. The old-old (those 85 years and over) show much higher nursing home utilization rates than their younger counterparts. As table 2 shows, for women 85 years and over the rate of nursing home use per 1000 population is 251.5 as compared to only 15.9 for females 65-74, and 80.6 for females 75-84. A similar pattern exists for men, although their nursing home utilization rates are lower.

15/ Changing Mortality Patterns. Health Services Utilization and Health Care Expenditures: United States 1978-2003, Analytical and Epidemiological Studies Series 3, no. 23, National Centers for Health Statistics, Department of Health and Human Services, Pub. No. (PHS) 83-1407, Sept. 1983. p. 20.

TABLE 2. Age-Specific Rates of Nursing Home Utilization per 1,000 Population, by Sex

Sex and age	Rates per 1,000 population
	Nursing home residents
Male	
65-74	12.7
75-84	47.4
85+	140.0
Total 65+	30.7
Female	
65-74	15.9
75-84	80.6
85+	251.5
Total 65+	59.7

Source: Rice, Dorothy and Jacob J. Feldman. Living Longer in the United States: Demographic Changes and Health Needs of the Elderly. Milbank Memorial Fund Quarterly/Health Society, v. 61, no. 3, 1983. Table 6. p. 376. Data are from the National Nursing Home Survey of 1977.

For every person 65 years of age and over residing in a nursing home, there are twice as many persons living in the community requiring similar levels of care. 16/ The 1979 National Health Interview Survey found that 12 percent of the population age 65 and over needed the help of another person in carrying out everyday activities and managed to live in the community despite chronic disability. 17/ Preliminary analysis from the 1982 National Long-Term Care Survey found approximately 4.6 million non-institutionalized elderly Americans, or 18 percent

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16/ Doty, Pamela, Korbin Liu, and Joshua Wiener. And Overview of Long-Term Care. Health Care Financing Review, v. 6, no. 3, spring 1985. p. 70.

17/ Feller, Barbara. Americans Needing Help to Function at Home. National Center for Health Statistics Advance Data, no. 92, Sept. 14, 1983. p. 7.

of the over 65 population, had limitations in ADLs and IADLs. 18/ As discussed above, limitations in ADLs reflect dependence in certain basic self-care functions such as bathing, dressing, eating, etc., and limitations in IADLs refer to lower levels of disability in the performance of a daily routine, including shopping, cooking, and cleaning. The 1982 Long-Term Care Survey found that two-thirds of the 4.6 million disabled non-institutionalized elderly living in the community were moderately impaired with one or two ADL limitations or only IADL limitations. About 850,000 elderly individuals were residing in the community with severe limitations (five or six ADLs).

This same preliminary analysis found that most of these disabled elderly received personal assistance in activities of daily living from spouses, children or other informal sources of support. 19/ Of the 4.6 million disabled elderly in the community, almost 70 percent relied exclusively on nonpaid sources. This finding corresponds to other research that has estimated that between 60 and 80 percent of the care received by the impaired elderly is provided by relatives and friends who are not compensated. 20/

It should be noted that the aging of the Nation's population has important implications for the availability of informal family sources of support for long-term care. Because of differences in mortality at all ages, older women are much more likely to be widowed than older men and are, therefore, at greater risk of institutionalization. In 1983, 9.0 percent of men aged 65 to 74 were widowed

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18/ Liu, Korbin, Kenneth Manton, and Barbara Liu. Home Care Expenses for Non-institutionalized Elderly with ADL and IADL Limitations. Unpublished paper, Apr. 23, 1985. p. 9.

19/ Liu, Manton, and Liu, p. 9.

20/ Long-Term Care: Background and Future Directions. Health Care Financing Administration, Department of Health and Human Services. Jan. 1981, HCFA 81-20047.

in contrast to 39.2 percent of women. The difference increased with age: among persons 75 and over, 21.7 percent of men and 66.6 percent of women were widowed.

In addition, the ability of children to support disabled parents may diminish. As the population ages, very old chronically ill parents with children who themselves are retired or chronically impaired become more common. 21/ Researchers have noted that the probability of young elderly (aged 65-69) women having at least one surviving parent aged 85 or older will more than double over the next 60 years. 22/ In addition, increased participation by women in the labor force may also decrease the amount of time they can spend on informal care of their relatives. Gerontologists have also noted the stress experienced by certain caretakers who have multiple roles--participation in the labor force and caretakers of children as well as disabled relatives.

21/ Long-Term Care: Background and Future Directions. p. 12.

22/ Saldo, Beth J. and Kenneth G. Manton. Health Status and Service Needs of the Oldest Old: Current Patterns and Future Trends. Milbank Memorial Fund Quarterly/Health and Society, v. 63, no. 2, spring 1985. p. 310.

II. PUBLIC SECTOR PROGRAMS FOR FINANCING AND DELIVERY OF LONG-TERM CARE SERVICES

Implicit in any discussion of long-term care policy is the fact that large amounts of public dollars currently finance long-term care services, and that even greater amounts will be spent in the future as the elderly population, especially the very old, increases. Aggregated data on spending for all nursing home and non-institutional long-term care services under the complete array of Federal, State and local programs are not easily available. At least 80 Federal programs alone assist persons with long-term care problems, either directly or indirectly through cash assistance, in-kind transfers, or the provision of goods and services. In addition, differences in definitions of services to be included in long-term care and inconsistent reporting across programs make aggregation of expenditure data very difficult.

However, it is generally agreed that most of the public sector's expenditures for long-term care services are for nursing home or other institutional care. In 1983, nearly $29 billion was spent nationally for nursing home care, accounting for 8.5 percent of total personal health care expenditures. Almost 50 percent ($14 billion) of nursing home expenditures was financed by Federal, State, and local governments.

By far the largest portion of public expenditures for nursing home care is financed by the Medicaid program for the poor and medically indigent. In 1983, Federal, State, and local Medicaid expenditures for nursing home care amounted to $12.4 billion. This represented 43 percent of total national spending on nursing home care and 89 percent of public spending for nursing home care in

1983. Medicaid's expenditures for nursing home care also represented a significant portion of total Medicaid spending. In 1983, Medicaid nursing home expenditures amounted to about 43 percent of total Medicaid spending for all health services covered under the program. In addition, an analysis of Medicaid expenditures found that 27 States spent 50 percent or more of their Medicaid budgets on nursing home care in 1982. 23/

By way of contrast, the Medicare program for the aged and disabled accounts for only a small portion of the Nation's expenditures for nursing home care. Medicare's expenditures amounted to $500 million and represented less than 2 percent of national spending and 3.6 percent of public spending for nursing home care in 1983.

Expenditures for non-institutional community-based services are relatively small compared to spending for nursing home services. Whereas nursing home care accounted for about 43 percent of total Medicaid expenditures for health care services in 1983, home health care accounted for only 1.8 percent of total Medicaid spending in that year and amounted to approximately $600 million. In only 11 States did home health benefits constitute more than one percent of total Medicaid expenditures. One State (New York) alone accounted for nearly 80 percent of total Medicaid home health expenditures.

Medicare's expenditures for home health benefits are also a small proportion of total expenditures. In 1983, they amounted to $1.5 billion, or 2.7 percent of total program expenditures.

It should be noted that while its share remains small, home health care has become one of the fastest growing components of both the Medicare and Medicaid budgets. Between 1974 and 1983, home health care expenditures under Medicare

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23/ Short-Term Evaluation of Medicaid: Selected Issues. Department of Health and Human Services, Health Care Financing Administration, Office of Research and Demonstrations, no. 84-9. July 1, 1984.

increased from $119 million to $1.5 billion. This represented a 32.5 percent annual compound rate of growth. Medicaid expenditures for home health also increased rapidly--from $31 million in 1974 to $600 million in 1983, a 39 percent annual compound rate of growth.

While the Medicaid program is the predominant Federal program supporting long-term care services, a variety of social service programs provide community-based services which may prevent or delay institutionalization. Chief among these are the Social Services Block Grant program and the Older Americans Act. While their total resources are small in comparison with total Medicaid expenditures devoted to long-term care, in many communities they represent an important source of service to the frail elderly or fill gaps in services not met by either the Medicare or Medicaid programs.

Virtually all States provide a number of home and community-based long-term care services for diverse client groups, including children, disabled, and the elderly, through the Social Services Block Grant (SSBG) program under title XX of the Social Security Act. Such services may include homemaker, home health aide, chore, and adult day care services. In some recent years expenditures for homemaker services alone have represented the second or third largest service expenditure category under the program. In addition, the increase in homemaker service expenditures from 1979 to 1980 (from $391.6 million to $410.9 million) was attributed to expanded use of funds for the elderly. For FY 1980 the average number of persons receiving this service was over 275,000 per quarter. Because Federal reporting requirements for services supported by the program have been eliminated, more recent national data on total expenditures and persons served are unavailable.

Home care, including homemaker, chore, and personal care services, is one of the major service categories under title III of the Older Americans Act. For FY 1984, it was estimated that the program would support over two million home care visits to the elderly. The Older Americans Act also authorizes a home-delivered meals program, with $62 million appropriated for FY 1984. An estimated 67 million home-delivered meals were served under auspices of the program during FY 1984.

A. Major Federal Programs Supporting Long-Term Care Services

As noted above, at least 80 Federal programs assist persons with long-term care problems, either directly or indirectly through cash assistance, in-kind transfers, or provision of goods and services. These programs often respond in a manner that is problem-specific, categorical in nature, or targeted at specific client groups. For example, certain programs provide health services while excluding social services; others are oriented to the elderly to the exclusion of the younger disabled. Some programs carry income eligibility requirements, others do not.

This section describes selected Federal programs--Medicaid, Medicare, the SSBG, Older Americans Act, and Supplemental Security Income (SSI) programs--which address the health and social services needs of the elderly population. Taken together, these programs constitute the major focus of Federal financial support presently available for both community-based and the institutional long-term services. The differing characteristics of these programs reflect what some observers point out to be the uncoordinated nature of Federal support for long-term care services.

Not discussed here are a host of other Federal programs dealing with such components of the long-term care spectrum as housing, transportation, tax policy as well as services provided through the Veterans Administration (VA). It should be noted, however, that numerous long-term care benefits are offered to veterans through the VA, including nursing home care, domiciliary care, outpatient clinics, and adult day health services, as well as cash payments for aid and attendance for certain severely disabled veterans. Services are offered directly by the VA and are also provided on a contract basis in non-VA hospitals and community nursing homes, and on a grant basis in State veterans' home facilities. Issues surrounding the financing and delivery of long-term care services to the veteran population are of increasing concern to the VA because of the growing number of older veterans. By the year 2000, approximately two out of every three males age 65 or older will be veterans and the VA is predicting dramatic increases in the need for and utilization of various long-term case services by the veteran population.

The discussion immediately below summarizes some of the major differences of the Medicaid, Medicare, Social Services Block Grant (SSBG), Older Americans Act, and SSI programs in their approach to health and social services in general and long-term care in specific. This discussion is followed by a more detailed description of each of these programs.

- PROGRAM GOALS. Medicaid is the major Federal program financing health care services for certain low income persons. While it provides health care benefits, and to a limited degree, medically related social services, to certain eligible persons with chronic care needs, it is not designed to support the full array of long-term care services on a systematic basis. Its principal form of support for long-term care services is for nursing home care. Medicare, on the other hand, is a nationwide health insurance program for the aged and disabled and is intended primarily to address acute medical care needs. To the extent that it provides coverage for certain long-term care services, it does so with the intent of reducing the need for more intensive and expensive acute care services; the program was not designed to respond specifically to chronic care needs of the elderly over a sustained period of time. The SSBG program is designed to assist families and individuals in maintaining self-sufficiency and independence; however, the program is generally limited to the provision of community-based social services selected and defined by each State and does not support institutional care. The Older Americans Act is intended to foster the development of a broadly defined, comprehensive and coordinated aging service system; however, it is limited in its ability to have a significant impact on long-term care due to its small level resources as compared to other programs. The SSI program's purpose is to provide an income floor for needy aged, blind, and disabled individuals; it provides cash payments but not services.

- ADMINISTRATIVE AUTHORITY AND FINANCING MECHANISMS. The Medicare program is administered and financed at the Federal level with uniform national standards. The Medicaid, SSBG, and Older Americans Act programs are shared Federal-State programs with States responsible for implementation of Federal legislation and regulations. The SSI program is administered by the Federal level but allows States to augment the Federal SSI payment and this portion of the program may be federally or State-administered. The Medicaid and Older Americans Act programs carry specific requirements for States to match Federal funds, whereas the SSBG does not. By virtue of their statutory obligations to beneficiaries, Medicare, Medicaid, and SSI represent uncontrollable expenditures in the Federal budget. In contrast, the total funding available for programs under the Older Americans Act is subject to an annual limit imposed through the appropriations process. Although the SSBG is considered an entitlement program to States, it carries a statutorily imposed Federal expenditure ceiling.

- SERVICE BENEFITS, DEFINITIONS, AND STANDARDS. As a general rule, Medicare and Medicaid provide reimbursement primarily for medical and health care services; however, in certain instances Medicaid reimbursement is available for social service components of health care services, e.g., under State options for personal care or adult day care service and under home and community-based waiver provisions. The SSBG program provides reimbursement for social services only but will provide coverage for medical care when such care is "integral but subordinate" to the provision of a social service. Funding under title III of the Older Americans Act is to be used for the development of a service delivery system for older persons, focusing on supportive and nutritional services. Recipients of SSI receive a cash payment which is federally determined but States may decide how much and for what purpose to supplement the Federal payment. Definitions for similar or complementary services vary among programs and sometimes among programs within a single State. Certain service definitions are established at the State level, or at the local level by individual service providers. Similarly, standards for services may be established upon legislative specifications.

- ELIGIBILITY. Entitlement for Medicare is generally based on Social Security status. Eligibility for Medicaid is linked to actual or potential receipt of cash assistance under the federally-assisted Aid to Families with Dependent Children program and the SSI program for the aged, blind, and disabled. The SSBG does not require that applicants or recipients meet income eligibility guidelines, although States may set standards. The Older Americans Act program prohibits income testing for services; however, funds under the program must be directed toward those with the greatest social or economic need. Eligibility for the Federal payment portion of SSI is based on federally established income and asset rules.

1. Medicaid--Title XIX of the Social Security Act

The Medicaid program is a Federal-State matching program providing medical assistance for certain low-income persons. Each State administers its own program and, subject to Federal guidelines, determines eligibility and scope of benefits. *In general, each State also determines the payment rate for services* provided to Medicaid recipients. The Federal Government's share of medical expenses is tied to a formula based upon the per capita income of the State. As a minimum, the Federal Government will pay 50 percent of the costs of medical care; this amount ranges up to 78 percent in the lower per capita income States.

The States vary greatly with regard to services they include in their plans and groups eligible to receive these services. For example, major long-term care services provided under Medicaid include intermediate care facility (ICF) services, skilled nursing facility (SNF) services, and home health services. Other Medicaid services sometimes associated with the needs of long-term care patients include: private nursing services, clinic services, physical therapy and related services, inpatient care for patients 65 years of age or older in institutions for mental diseases or tuberculosis, inpatient psychiatric services for individuals under the age of 21, personal care services at home, and adult day health services. However, not all States cover these services equally. In addition, States may cover certain other home- and community-based services under special waiver programs reviewed and approved by the Secretary of Health and Human Services.

Medicaid law requires that States cover under their programs the "categorically needy"--all persons receiving assistance under the Aid to Families with Dependent Children (AFDC) program and most persons receiving assistance under the SSI program. States may also cover additional persons as categorically needy. These might include persons who would be eligible for cash assistance, except that they are residents in medical institutions, such as skilled nursing or intermediate care facilities.

In addition to the categorically needy, States may at their option cover the "medically needy," persons whose income and resources are large enough to cover daily living expenses, according to income levels set by the State, but not large enough to pay for medical care. If the income and resources of the "medically needy" individual are above a State-prescribed level, the individual must first incur a certain amount of medical expense which lowers the income to the medically needy levels (so-called "spenddown" requirement). Thirty-four States and jurisdictions cover the medically needy. As a result of State variations such as these, persons with identical circumstances may be eligible to receive Medicaid benefits in one State but not in another; even individuals in the same State with similar incomes may not be equally eligible for benefits due to welfare rules.

Observers have noted that Medicaid's eligibility policies and benefit structure have actually created financial incentives to use nursing homes rather than community services. In general, Medicaid support to the chronically impaired elderly living in the community has usually been quite limited. In addition, certain elderly poor who are ineligible for Medicaid while living in the community may become eligible once they enter a nursing home because the State has a higher income eligibility standard for nursing home residents. Others become eligible for Medicaid once they deplete their resources after entering the nursing home as privately paying patients. The 1983 GAO report on "Medicaid and Nursing Home Care" noted studies showing that one-quarter to two-thirds of Medicaid patients in nursing homes initially entered as private paying patients and subsequently converted to Medicaid. 24/ Another analysis completed for the House Select Committee on Aging found that in Massachusetts 63 percent of elderly persons aged 66 and older living alone in the community will deplete their assets after only 13 weeks in a nursing home, and for married couples aged 66 years and older, 37 percent will do so within 13 weeks if one spouse requires nursing home care. 25/

In order to allow States to broaden coverage for a range of community-based services and to receive Federal reimbursement for these services, Congress in 1981 enacted new authority for the Department of Health and Human Services (DHHS) to waive certain of Medicaid's requirements. Specifically, section 2176 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35) authorizes the Secretary of DHHS to approve "2176 waivers" for a variety of home and community-based services for individuals who, without such services, would require the level of care provided in a skilled nursing facility or intermediate care facility. Under the 2176 authority, the Health Care Financing Administration (HCFA), the DHHS agency which administers the Medicaid program, is allowed to waive two specific Medicaid requirements: (1) a requirement that Medicaid services be available throughout a State and (2) a requirement that covered services be equal in amount, duration, and scope for certain Medicaid recipients. By allowing the Secretary to waive these requirements, States are given flexibility to offer se-

rather than in all geographic jurisdictions as would be required absent the

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24/ Medicaid and Nursing Home Care: Cost Increases and the Need for Services are Creating Problems for the States and the Elderly. U.S. General Accounting Office, GAO/IPE-84-1. Oct. 21, 1983. p. 25-26.

25/ U.S. Congress. House. Select Committee on Aging. America's Elderly at Risk. Pub. No. 99-508, July 1985, Washington, D.C. Research analysis completed for the Committee by Dr. Laurence Branch, Dr. David Friedman, and Ms. Elinor Socholitzky.

waiver, and to offer selected services to certain State-defined individuals eligible for Medicaid assistance, including the aged, blind, disabled, mentally retarded, and mentally ill, rather than offering such services to all persons in particular groups. In addition, States have been able to extend to waiver participants the more liberal Medicaid income eligibility rules that may be applied to persons in institutions.

The expanded services which States may offer under an approved waiver include medical and medical-related services as well as social services. Prior to the implementation of the 2176 waiver program, Medicaid services available to chronically ill or disabled individuals living in the community were generally restricted to medical and medical-related services. The waiver authority acknowledges that a wide variety of services may be needed in order to prevent or avoid institutionalization. For this reason, services traditionally considered to be social services are covered in the waiver authority. These include case management (commonly understood to be a system under which responsibility for locating, coordinating, and monitoring a group of services rests with a designated person or organization), homemaker and chore services, adult day health, and respite care.

The additional flexibility Congress authorized under the waiver as to services, eligibility, and geographic areas to be covered was qualified by a concern about the costs of home and community-based care to be provided under the amendment. Therefore, the law included a requirement that States demonstrate that the costs of services for individuals receiving home and community-based services not exceed the cost to Medicaid of care in institutions.

As of June 30, 1985, HCFA had approved 107 waivers in 46 States. For more information about the 2176 waiver program, see CRS white paper, Medicaid 2176 Waivers for Home and Community-Based Care, 85-817 EPW.

2. Medicare--Title XVIII of the Social Security Act

Medicare is a Federal health insurance program with a uniform eligibility and benefit structure throughout the United States. The program covers most individuals entitled to Social Security benefits, persons under 65 entitled to Federal disability benefits, and certain individuals with end-stage renal disease. Coverage is available to persons without regard to their income or assets.

Medicare is generally not regarded as a program intended to provide support for long-term care. Its coverage is focused primarily on acute care, particularly hospital and surgical care and accompanying periods of recovery. For example, Medicare covers up to 100 days of skilled nursing facility (SNF) services following a hospital stay of at least three consecutive days. The benefit is further limited in that the patient must be in need of skilled nursing care on a daily basis for treatment related to a condition for which he or she was hospitalized. The SNF benefit is subject to a daily patient copayment after the 20th day of care. The program pays for neither intermediate care facility services nor custodial care in a nursing home.

Medicare does pay for some community-based long-term care services, primarily home health services. Home health services covered under Medicare include the following:

--part-time or intermittent nursing care provided by, or under the supervision of, a registered professional nurse;

--physical, occupational, or speech therapy;

--medical social services provided under the direction of a physician;

--medical supplies and equipment (other than drugs and medicines);

--medical services provided by an intern or resident enrolled in a teaching program in a hospital affiliated or under contract with a home health agency; and

--part-time or intermittent services provided by a home health aide, as permitted by regulations.

To qualify for home health services, the Medicare beneficiary must be confined to his/her home and under the care of a physician. In addition, the person must be in need of part-time or intermittent skilled nursing care or physical or speech therapy. Services must be provided by a home health agency certified to participate under Medicare, according to a plan of treatment prescribed and reviewed by a physician. There is no statutory limit on the number of home health visits covered under Medicare. Nor is the patient subject to any cost-sharing, e.g., deductibles or coinsurance, for covered home health services.

In addition to these SNF and home health care benefits, Medicare covers a range of long-term care services, and especically home care services, for terminally ill beneficiaries. These services, authorized in 1982 and referred to as Medicare's hospice benefit, are available to beneficiaries with a life expectancy of 6 months or less. Hospice care benefits include nursing care, therapy services, medical social services, home health aide services, physician services, counseling, and short-term inpatient care. For FY 1985, the Health Care Financing Administration estimates that Medicare expenditures for hospice care will amount to $15 million.

3. Social Services Block Grant Program--Title XX of the Social Security Act

Title XX of the Social Security Act authorizes a block grant to States for a wide range of social services to diverse population groups, including the aged, disabled, and children. States are allowed considerable discretion in their support of social services as long as the services are structured to meet the following goals of the program: achieving or maintaining economic self-support and self-sufficiency; preventing or remedying neglect, abuse, or exploitation;

preventing or reducing inappropriate institutional care by providing for community-based care; and securing referral or admission for institutional care when other forms of care are not appropriate, or providing certain services to individuals in institutions (excluding room and board). The SSBG provides reimbursement for social services only, but will provide coverage for medical care when such care is "integral but subordinate" to the provision of a social service.

States receive allotments of SSBG funds on the basis of the State's population, within a Federal expenditure ceiling. There are no requirements for use of title XX funds--States are provided relative freedom to spend Federal social service block grant funds on State-identified service needs. Legislation in the 98th Congress permanently increased the expenditure ceiling to $2.7 billion, effective in FY 1984; in FY 1985 the appropriation level is $2.7 billion.

The title XX program was significantly changed by provisions of P.L. 97-35, the Omnibus Budget Reconciliation Act of 1981, effective in FY 1982. Through FY 1981, the program contained certain limited requirements regarding the population to be served and the kinds of services to be provided to families and individuals. Under provisions of P.L. 97-35, States have been given much more discretion in determining the service population and services to be offered. The law eliminated requirements that States expend a portion of funds for welfare recipients, that services be limited to families with incomes below 115 percent of the State median income, and that fees be charged to persons with specified income levels. While previous State planning requirements were lessened, the law continues to require States to develop and make public a report on how funds are to be used prior to the State plan period, including information on the types of activities to be funded and the characteristics of individuals to be served.

The 1981 law also eliminated State reporting requirements; therefore, only very limited data are available as to the extent to which title XX suports long-term care services. According to a DHHS analysis of the States' FY 1985 pre-expenditure reports under title XX (a report on States' intended use of funds), home care services, which may include homemaker, chore, and home management services, were to be provided by virtually all States (to adults and children); adult day care by 26 States; and adult foster care by 16 States.

According to data compiled by the American Public Welfare Association for a limited number of States, home-based services were provided in 1983 to 11 percent of total title XX recipients, or about 307,000 persons of all ages. Home-based services accounted for about 14 percent of total expenditures, or $555 million (out of a total estimated amount of Federal and State funds of $4 billion). 26/ It should be noted that these data are for total title XX recipients; national data specific to the elderly and disabled population and by service are unavailable.

Although the SSBG represents the major social service program supported by the Federal Government, its ability to support significantly the long-term care population is relatively limited. Because it provides a variety of social services to a diverse population, the program has competing demands. Community care programs such as those supported by title XX are minimal when compared to programs which support institutional care. For example, Federal funds available for all title XX activities in 1983 ($2.7 billion) were approximately one-third the total Federal nursing home expenditures in that year ($8.1 billion).

26/ Data were compiled by the American Public Welfare Association under its Voluntary Cooperative Information System under which States voluntarily report data on their social service programs. Data for recipients are for 32 States and expenditures are for 31 States. Total expenditures including a combination of State and local funds, Federal title XX funds, and other funds for 31 States, were an estimated $4 billion in 1983.

4. The Older Americans Act

The Older Americans Act carries a broad mandate to improve the lives of older persons in the areas of income, emotional and physical well-being, housing, employment, social services, civic, cultural, and recreational opportunities.

The purpose of title III of the Act, which authorizes formula grants to States for services to older persons, is to foster the development of a comprehensive and coordinated service system for older persons in order to (a) secure and maintain maximum independence and dignity in a home environment for older persons capable of self-care; (b) remove individual and social barriers to economic and personal independence for older persons; and (c) provide a continuum of care for the vulnerable elderly. Under title III, grants are made to State agencies on aging, which in turn award funds to 664 area agencies on aging, to plan, coordinate, and advocate for, a comprehensive service system for older persons. Title III supports a wide range of supportive services, as well as congregate and home-delivered nutrition services. Certain supportive services have been given priority by Congress, including in-home services, such as homemaker and home health aide, visiting and telephone reassurance, and chore. Each area agency is required to spend a portion of its supportive services allotment on these services. Other community-based long-term care services which may be provided under title III include case management, assessment, adult day care, and respite care, among others. Services under the title III program are to be provided to older persons without regard to income, although concentrated on those with the greatest social or economic need. Older persons are to be given the opportunity to contribute to the cost of services, but failure to do so cannot be a basis for denial of service.

Unlike the title XX program in which States receive a block of funds for unspecified social services, Congress makes separate appropriations of title III funds for supportive services, for congregate nutrition services (in which older persons receive meals and other services in a group setting), and for home-delivered nutrition services. States receive allotments of these funds according to the number of older persons in the State as compared to all States. The law gives States and area agencies flexibility to define the supportive services to be provided and to transfer funds among the three service categories. Total FY 1985 appropriations for title III are $669 million, with 50 percent, or $336 million, for congregate nutrition services, and 40 percent, or $265 million for supportive services. Only about 10 percent of the Federal appropriation, or $68 million, is devoted to home-delivered nutrition services. 27/

In-home services clearly represent an expenditure priority for the title III program. According to the National Data Base on Aging, in 1984, about one-quarter of funds controlled by area agencies (including Older Americans Act funds as well as non-Older Americans Act funds) was directed at in-home services. While a substantial portion of these funds was spent on the home-delivered meals component, which receives a separate appropriation under the Act, almost an equal proportion of the total spent on in-home services was devoted to housekeeping, personal care, and chore services. 28/

The ability of the Older Americans Act to have a significant impact on the long-term care system is limited due to its relatively small level of resources as compared to other programs. However, many State and area agencies have made strides to improve long-term care services through coordination activities

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27/ Title III funding also includes appropriations for U.S. Department of Agriculture commodities or cash-in-lieu of commodities; $120.8 million is available in FY 1985.

28/ Data are from a random sample survey of 121 area agencies on aging in 1984. Supplied by the National Data Base on Aging, a service of the National Association of State Units on Aging and the National Association of Area Agencies on Aging.

with health and other social service agencies, and through the development of a social service infrastructure for the elderly at the local level. Some State agencies on aging have also acted as catalysts to reorganize community-based health and social services systems at the State and local levels so as to serve more effectively the long-term care population. For example, State agencies have developed case management and assessment systems through area agencies on aging and have supported services otherwise unavailable to the frail population. In other cases, State agencies on aging have been given responsibility for the administration of the section 2176 home and community-based waiver program under Medicaid. Although the amount of funding which title III devotes to home care services may represent a small fraction of the amount spent for home health services under Medicare and Medicaid, the title III program has the flexibility to fill gaps in services for persons otherwise unserved. Since Older Americans Act services may be provided without the restrictions required under Medicare and without certain income tests specified for by Medicaid, in some cases title III funds may be used to serve persons whose Medicare and Medicaid benefits have been exhausted or who are ineligible for Medicaid.

Although the home-delivered nutrition program receives less Federal funding than the congregate nutrition program, in recent years States have increasingly shifted funds from the congregate program to the home-delivered and supportive services components. In FY 1984 States shifted over $41 million from the congregate nutrition appropriated amount of $321 million to the other service components. Reasons cited for this trend include the increasing age of the older population and increased demand for home-based services by a more frail and older population. A recent evaluation of the Older Americans Act nutrition program performed for the Administration on Aging has shown that recipients of home-delivered nutrition services tend to be older, poorer, and in worse health than congregate nutrition participants.

Another long-term care activity required under title III is the operation of a statewide long-term care ombudsman program. This authority requires State agencies to conduct the following activities: investigate and resolve complaints relating to the health, safety, welfare, and rights of institutionalized persons; monitor Federal, State and local laws, regulations, and policies with respect to long-term care facilities; provide information to public agencies regarding problems of older persons in long-term care facilities; and establish procedures for access to facilities' and patients' records, including protection of the confidentiality of such records. Ombudsman activities are to take place not only with respect to policies and practices of nursing homes but also activities in boarding homes. State agencies responsible for the ombudsman program have created sub-State programs to carry out these activities; in 1984 there were about 400 sub-State ombudsman programs. In FY 1983, about $12.1 million was expended for ombudsman activities under the Older Americans Act ($8.9 million in Federal funds and $3.2 million from State and local funds). 29/

5. Supplemental Security Income Program--Title XVI of the Social Security Act

The Supplemental Security Income (SSI) is a federally administered income assistance program authorized by title XVI of the Social Security Act. Enacted by the 1972 Social Security Amendments and implemented in 1974, it replaced previous programs of State income assistance for the aged, blind and disabled. The SSI program provides a minimum income level for aged, blind, and disabled persons whose countable income does not exceed the Federal maximum monthly SSI benefit.

29/ Data are from Administration on Aging testimony at a hearing before the House Select Committee on Aging, Sept. 10, 1985. Unpublished hearing record.

In 1985 the monthly Federal SSI benefit is $325 for an individual and $488 for a couple with no other income. SSI payments are made to individuals under uniform, nationwide rules with respect to income and assets, and definitions of blindness and disability. In 1985 an estimated 4 million individuals will receive Federal SSI payments (1.5 million aged persons and 2.5 million blind or disabled persons). 30/

The SSI program also allows States to supplement the Federal SSI payment through optional supplemental payments to individuals. All but eight States and jurisdictions provide some form of optional State payments. (These States are Arkansas, Georgia, Kansas, Mississippi, the Northern Mariana Islands, Tennessee, Texas, and West Virginia.) Each State determines whether it will make a supplemental payment, to whom, and in what amount. These State supplemental payments, also paid on a regular monthly basis, are intended to supplement the basic Federal SSI payment for food, shelter, clothing, utilities, and other necessities. Some States provide optional State supplemental payments to all persons qualifying for SSI benefits, while others may limit payments to certain State-defined SSI recipients, or may extend payments to persons who would be eligible for SSI except for excess income.

Because the Federal SSI payment may be insufficient to cover an individual's service needs which extend beyond room and board, such as non-medical supervision or other group living arrangements or personal care services, a significant number of States provide supplemental payments to support selected community-based long-term care services. These services often include supervision

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30/ This number includes persons receiving Federal SSI payments and/or Federally administered State supplementation.

of daily living or other protective housing services for the mentally retarded, chronically mentally ill, or the frail or confused elderly.

An analysis of optional State supplemental programs as of January 1985 shows that 35 States support a diverse range of community-based long term care services through their optional State supplementation programs. 31/ Payments are made to individuals to support their residence in a variety of housing arrangements such as adult foster care homes, domiciliary care homes, congregate care facilities, adult residential care homes, and shared homes for adults. In addition to providing payments for specialized housing arrangements, some States also provide supplemental payments to pay for personal care, home health and other home care services for eligible individuals.

B. Federal Research and Demonstration Initiatives

Over the last decade the Federal Government has supported a wide range of research and demonstration activities designed to test new ways of providing and coordinating long-term care services as well as to achieve costs savings in the provision of care. Federally funded demonstrations have been sponsored principally by the Department of Health and Human Services (DHHS), and within DHHS, by the Health Care Financing Administration (HCFA) and the Administration on Aging (AOA). In some cases, HCFA has waived Medicare or Medicaid service or eligibility requirements so that a fuller range of services may be provided to persons who would not ordinarily benefit under the existing programs.

31/ Information was compiled by CRS from The Supplemental Security Income Program for the Aged, Blind, and Disabled, Characteristics of State Assistance Programs for SSI Recipients, Social Security Administration, SSA Pub. No. 17-002. Jan. 1985.

Research and demonstration projects have ranged from those in which system-wide changes have been made in the provision of community services to those in which the existing service system has been modified by the addition of previously unavailable services. The organization, administration, auspices, funding source, and service packages have differed across demonstration projects; however, certain common features exist. Many projects were geared toward the development of procedures to provide assessment, case management, and follow-up of clients with long-term care needs in order to assure care in the least restrictive setting. Multidisciplinary teams (generally composed of medical, health, and social service professionals) were established to accomplish this objective. Most projects aimed to provide or access a range of health and health-related social services for specified client groups, including homemaker, home health, chore, home-delivered meals, adult day health, and transportation.

Most of these projects have terminated as Federal demonstrations, but most have been viewed as precursors to the DHHS National Long-Term Care Channeling Demonstration Program funded for the first time during FY 1980. Another more recent research and demonstration initiative is the Social/Health Maintenance Organizations (S/HMO) project.

1. National Long Term Care Channeling Demonstration

In 1980, three units within the Department of Health and Human Services, the Health Care Financing Administration, the Administration on Aging, and the Office of the Assistant Secretary for Planning and Evaluation, initiated the National Long-Term Channeling Demonstration. This project was designed to test whether a carefully managed approach to the provision of community-based long-term care services to a frail elderly population living outside institutions could help control overall long-term care costs while maintaining or improving the well-being of its clients.

The term "channeling" refers to organizational structures and systems which coordinate available long-term care resources and manage them effectively on behalf of clients. Channeling was expected to achieve its effects principally by substituting less costly community or informal services for more expensive institutional care. Ten States received multi-year demonstration funds, and, as of March 1985, all States had terminated the demonstration phase. The program, designed with treatment and control groups, was devised to answer questions which previous demonstrations had not totally answered, such as the cost of case management systems and how best to target community-based services on those who would otherwise be institutionalized. Other questions to be answered by the demonstration included: Does channeling reduce institutionalization and hospitalization? Is use of formal [illegible] services in the community increased? [illegible] What impact [illegible] care, on longevity [illegible]

Final results [illegible] March 1986. However, results of a preliminary analysis [illegible] early enrollees in the program indicate that the demonstration identified a very frail population with limited income living in the community. Of this early sample, 52 percent were incontinent, 22 percent were unable to perform activities of daily living, and 81 percent were restricted in mobility. A large majority needed assistance in preparing meals, shopping, and other housekeeping activities. In addition, 57 percent of the sample had income below $500/month.

2. Social/Health Maintenance Organization Demonstration

In 1980, the Health Care Financing Administration, DHHS, and private foundations began funding the development, planning, and operation of the S/HMO concept for financing acute and long-term care services for an elderly population eligible for Medicare and/or Medicaid. The S/HMO concept builds upon and extends the health maintenance organization (HMO) model for financing acute, medical care services. Specifically, an HMO offers health insurance coverage for specific health care services on a pre-paid, capitation basis (the premium charge for enrollment) and either provides directly, or arranges to have provided, the health services covered under the insurance contract. The HMO is at risk for the costs of the services it covers; that is, it will experience some level of profit or loss on the basis of its ability to estimate in advance its revenues and the utilization and costs of services it provides.

The success of conventional HMOs in managing acute medical care services and costs suggested the possibility of expanding the concept to include long-term care services. [illegible] sites [illegible] providing [illegible] which [illegible] elderly population eligible for Medicare and/or Medicaid. These persons will range from the ambulatory well aged to the impaired elderly. Medicare, Medicaid, and private premiums will finance the services.

Long-term care services covered by S/HMOs will include nursing home services, home health services, homemaker/home health aide services, personal care, adult day care, respite care, and home-delivered meals. Each S/HMO site will have its own defined long-term care benefit. Because of limited experience with long-term care insurance and utilization, long-term care services will be covered up to a maximum dollar amount per year and will require a copayment. The limits range from $6,500 per year to $12,000. In addition, S/HMOs will gradually assume full risk for the utilization and costs of covered services.

The four demonstration sites began providing services in 1985 and will continue to do so through June 1988. An independent contractor will evaluate all four sites. In general, the S/HMO demonstration is intended to provide information about the cost effectiveness of providing services in an integrated and managed system of care, its impact on the utilization of health and long-term care services by the elderly, and its effect on the quality of care available to the eligible population. Among the specific questions DHHS expects this demonstration to address are the following:

- Whether comprehensive long-term care insurance can be marketed to a significant number of elderly.
- What combination of benefits, eligibility criteria, premiums and marketing techniques [illegible]
- [illegible]
- [illegible]
- [illegible] aged system [illegible]
- Whether informal support (i.e., care provided by family members, friends and community volunteers) of chronically impaired elders is enhanced in a pre-paid, risk-based, case-managed health care system offering both acute and long-term care services.

C. State Level Initiatives

The fragmentation and lack of coordination among major Federal programs which support long-term care services have provided the States with major implementation challenges. The Medicaid, Social Services Block Grant, and Older Americans Act programs all delegate administration and implementation responsibility to the States, and, in so doing, require the States to deal with problems inherent in the different goals of these programs, as well as their varying eligibility requirements, service benefits, and reimbursement policies. These implementation problems have also resulted from the fact that fragmentation at the Federal level has been mirrored in State administration, with major long-term care programs being administered by different State agencies.

Many States have responded to these challenges by enacting legislation and/or creating initiatives to reorganize and restructure benefits offered through the Federal programs. Also, some States have consolidated the administration of various long-term care programs in a single State agency.

[illegible] long-term care practices [illegible] began [illegible] encouraged State and local agencies to merge existing health and social service funds available under Medicaid, Title XX, and the Older Americans Act to create the now more than 1000 adult day care programs in existence.

Certain parallel activities have been initiated by States without the benefit of Federal demonstration funds and without any changes in Federal legislation. A number of States have attempted to reduce the need for institutional care by redirecting existing Federal program funds or by using existing Federal and complementary State funds in new ways. For example, the Virginia State Medicaid agency operates a nursing home pre-admission screening program through local public health departments for persons likely to be admitted to a nursing home but whose needs could be addressed through community-based services. The Massachusetts State agency on aging has established community-based organizations to manage certain key home care services for older persons through creative use of title III Older Americans Act funds and State funds. The Utah State agency on aging has established a program to identify persons at risk of being institutionalized and has developed alternative community-based service plans using personnel of the State's area agencies on aging network.

The objective of reducing institutional care costs and diverting potential users to other forms of care has been the impetus behind much of the State effort to alter long-term care systems. Despite unclear evidence about the cost-effectiveness of substituting various forms of community-based care for institutional care, an enormous amount of State effort has been directed at developing community care options.

Some of the themes evidenced in State level initiatives include the following:

- Control of institutional access through screening/assessment procedures. Many States have initiated screening and comprehensive medical and social assessment procedures of those "at risk" of long-term care services in order to ascertain the most effective and least costly care option, given the client's needs. Such screening and assessment procedures are generally applied to persons about to enter a long-term care facility. A review of State Medicaid programs in 1981 showed that 28 States had mandatory preadmission screening programs for Medicaid patients prior to nursing home admission. [32]

- Reorganizing access to community services. Some States have devised projects aimed at reorganizing access to community services by providing case management services or "gateway" procedures for clients. This concept has been developed to overcome problems associated with multiple providers and duplication of services that have resulted in client confusion as to source of care and unneces-

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32/ Knowlton, Jackson, Steven Clauser, and James Fatula. Nursing Home Pre-Admission Screening: A Review of State Programs. Health Care Financing Review, v. 3, no. 3, March 1982. p. 78.

sary administrative costs among agencies. The availability of Medicaid funds under the 2176 home and community-based service waiver program has recently spurred the development of many more case management systems but perhaps not on a statewide basis. Of the 95 2176 waiver programs approved as of April 30, 1985, 66 programs offered case management.

- Cost control mechanisms. Some States have eliminated the uncertainty of whether community care will exceed institutional care costs by pre-establishing upper cost limits on such care; for example, community care may be provided only when such care does not cost more than a certain percentage of institutional care. An example of this concept is contained in New York's Nursing Home Without Walls program. This cost control concept has been incorporated into the National Long-Term Care Channeling Demonstration program and is a basic element of the Medicaid 2176 home and community-based service waiver program.

- Tax incentives for dependent care. Many States permit favorable tax treatment for families or other caretakers who care for dependent older persons. According to a survey of the National Association of State Units on Aging, 27 States and the District of Columbia have adopted some form of dependent care tax credits, generally designed to assist in the care of dependents by adults who are working or seeking work. Of these 27 States, five have enacted tax provisions specifically designed to assist caregivers with the expenses of caring for older persons. These States are Arizona, Idaho, Iowa, North Carolina, and Oregon. 33/

33/ National Association of State Units on Aging. State Tax Policy Options for the Elderly: A Guide for Aging Advocates. May 1985. Washington, D.C. p. 46-47.

IV. PRIVATE SECTOR APPROACHES TO FINANCING AND DELIVERY OF LONG-TERM CARE

Budgetary constraints resulting from growing Federal deficits and increasing expenditures required under various entitlement programs which currently finance long-term care have served to shift the focus of the long-term care debate from reform of Federal programs to consideration of private sector initiatives which might relieve fiscal pressures on public programs and which at the same time may improve the elderly's ability to finance long-term care. Observers have also noted that the decline in the ratio of workers to retirees and the growth in numbers of the very oldest segment of the population may have a marked impact on the ability of public programs to support long-term care in the future. In addition, others point out that the economic status of future generations of the elderly may improve significantly and that they will therefore be able to pay for a larger portion of the cost of certain long-term care services.

The improvement in the economic status of certain groups of elderly may lead policy-makers to target public sector long-term care programs on the most needy income categories of elderly, while at the same time to encourage various private sector financing approaches which could assure greater protection against the cost of long-term care services for those who are relatively better off. However, at the current time, most elderly do not have the resources to pay for the catastrophic expenditures associated with certain long-term care services over an extended period of time. For many, depletion of assets and income for the cost of care and subsequent Medicaid eligibility is the only remedy.

A number of private sector approaches have recently been suggested as potentially feasible alternatives for financing long-term care services. These range from ways to pool risks associated with long-term care need through private insurance and life care communities to conversion of an elderly homeowner's equity into a source of funds to pay for care. A discussion of these approaches and their feasibility for financing long-term care follows. It should be noted that these private sector alternatives may have only limited applicability for the large number of elderly who are poor or may be poor in the future. Another method of risk pooling, the social/health maintenance organization, was discussed above in the section on public training and delivery. This report does not discuss still other options suggested as feasible alternatives for enhancing the elderly's ability to finance long-term care expenses, including the various tax code modifications proposed to encourage families to continue providing long-term care service.

A. Private Health Insurance Coverage for Long-Term Care

Among the private sector approaches receiving increased attention recently as a potential alternative for financing long-term care services is private health insurance. This alternative has been suggested not only because of growing fiscal constraints on public program expenditures, but more basically because private insurance coverage is currently available for a wide variety of health care services and catastrophic illness, but generally not for long-term care services or the catastrophic costs associated with long-term care.

Expenditures for long-term services, and especially for nursing home care, not only strain the budgets of public programs; they are also a burden on private resources. In 1983, total national nursing home expenditures of $29 billion were financed about equally by public programs and private sources of payment. Public programs financed $14 billion of the total and private sources $15 billion. Of total private spending for nursing home care in 1983, only two percent was paid by private insurance coverage. Ninety-seven percent of the total private spending for nursing home care was paid directly by the consumer out-of-pocket. The average annual cost of nursing home care exceeds $20,000 per year, representing a catastrophic expenditure beyond the financial reach of most elderly. 34/

In addition, private insurance coverage has been viewed as a feasible alternative because of general interest among the elderly population in purchasing private insurance to supplement their Medicare benefits. Nearly two-thirds of the elderly currently purchase such "medigap" policies. While these policies generally pay only certain deductible and coinsurance amounts for which Medicare beneficiaries are liable and do not cover long-term care, the widespread interest of the elderly in this broader coverage suggests to some observers that a market for long-term care coverage can and does exist.

Furthermore, evidence indicates that the elderly will have higher incomes and assets in the future which will enable them to afford premiums for coverage. One study has estimated that given future income levels and growth of pensions, approximately 93 percent of all married couples at age 65 and almost 60 percent of all single persons at that age would be able to purchase long-term care insurance with less than five percent of their cash income by the year 2005. 35/

34/ Doty, Liu, and Wiener, p. 74.

35/ Private Financing of Long-Term Care: Current Methods and Resources. ICF, Inc., Final Report Submitted to the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, Phase I, Jan. 1984. p. 79.

Currently, relatively few insurance companies (studies indicate 16 to 25) write long-term care insurance policies which are substantially more comprehensive than standard medigap policies and which go beyond restrictive Medicare definitions for skilled nursing care to include intermediate and custodial care. It is estimated that about 50,000 elderly persons are presently insured under such plans. 36/ *Premiums for most of the available policies* increase with age of initial purchase. The plans vary by length of time benefits are covered, waiting periods before benefits can begin, and the conditions upon which benefits will be paid. Most plans provide indemnity benefits, paying a fixed amount for each day of covered service, thereby limiting the insurers' liability. In addition, most have utilization controls to further limit an insurer's liability and to protect the insurer against unnecessary utilization of benefits. These include medical screens and physical examinations for utilization of benefits, preexisting condition restrictions, prior hospitalization requirements, exclusion of mental and nervous disorders, and renewability limitations. Home care benefits, especially those related to custodial or personal care, are included in even fewer long-term care insurance policies. Often plans that cover any home care at all require a prior stay in a skilled nursing facility in order to reduce the large potential demand for home care among the majority of the covered population that has never been institutionalized. 37/

36/ Private Financing of Long-Term Care, p. 12. For a review of plans, see also, Meiners, Mark. The State of the Art in Long-Term Care Insurance. Long-Term Care Financing and Delivery Systems: Exploring Some Alternatives. Conference Proceedings. Health Care Financing Administration, Department of Health and Human Services, Jan. 24, 1985.

37/ Increasing Private Financing of Long-Term Care: Opportunities for Collaborative Action. SRI International, Aug. 1985. p. 14.

A number of barriers have been cited as impediments to the development of meaningful long-term care insurance policies. 38/ Traditionally, insurers have been concerned about the potential for adverse selection in long-term care insurance, where only persons more likely to need care actually buy insurance. In addition, insurers point to the problem of the induced demand for services that can be expected to be generated by the availability of new long-term care insurance. With induced demand, individuals decide to use more services because they have insurance and/or will shift from non-paid to paid providers for their care. This is especially critical in long-term care with 60 to 80 percent of disabled or impaired persons receiving home care services from family or friends who are not compensated.

Still other factors are mentioned as problems inhibiting the development of long-term care policies. Many long-term care services that are felt to be critical in enabling frail elderly persons to remain in their homes are custodial, non-medical services. Traditionally these services, such as personal care, homemaker, and nutritional services are considered noninsurable because of difficulty in confining eligibility to a limited number of people. In addition, observers have noted that, given the nature of many chronic conditions, many people who need long-term care will need it for the remainder of their lives, resulting in an open-ended liability for the insurance company. Moreover, evidence exists that the elderly do not understand their insurance coverage or their potential need for long-term care. Some elderly believe they are already adequately covered for such services under Medicare while others think they

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38/ Long-Term Care: The Challenge to Society. Health Insurance Association of America, 1984.

have coverage for long-term care with their purchase of a medigap policy. 39/ Therefore, they do not demand specific coverage for long-term care.

According to a study of the Health Insurance Association of America (HIAA), one of the most significant barriers to the development of private insurance options is the major role played by Medicaid in financing long-term care and especially nursing home services. According to the HIAA report, Long-Term Care: The Challenge to Society, Medicaid is already viewed by many as a national coverage program for long-term nursing home care, used by far more than the low income population usually thought of as Medicaid's primary clients. In addition, the ability of individuals to plan for the transfer of assets expands the number of persons eligible for long-term care benefits under the program. According to HIAA's report, public programs are viewed as a safety net providing protection against the catastrophic costs of care. The report calls for reduced Medicaid involvement in financing nursing home care so that fewer middle income individuals can view the program as a viable option for their long-term care needs.

As noted above, the number of long-term care insurance policies providing meaningful protection for the at-risk elderly population is very limited. However, recent research suggests that many of the barriers that are commonly thought to preclude the development of long-term care insurance are subject to resolution by careful policy specification, including limitations on number of days covered, waiting periods before benefits can begin, and maximum amounts payable. 40/ In addition, research has found that significant reductions in annual premium rates could be offered if persons were encouraged to buy at younger ages and to accept longer periods before coverage begins and shorter length

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39/ Meiners, Mark. The Case for Long-Term Care Insurance. Health Affairs, v. 2, no. 2, summer 1983. p. 57.

40/ Meiners, The Case for Long-Term Care Insurance.

of coverage for benefits. 41/ Others have suggested that allowing families to purchase protection for their elderly parents could make long-term care insurance a more feasible option. Adding adult children, who have a much lower risk of incurring long-term care expenses for themselves, to the pool of the insured could expand premium collections and at the same time make a policy more affordable. The adult children could pay for the premiums on behalf of their elderly relatives as well as themselves, but presumably they would not begin to make claims for long-term care services on their own behalf until some future time.

Non-traditional health insurance alternatives have also been advanced as viable options for long-term care financing. Some have suggested that long-term care services can be controlled only in a managed care system, such as an HMO. The social/HMO demonstration project described above will provide information about the feasibility of this approach. In addition, some have pointed to tax-preferred cash accumulation plans, such as individual retirement accounts (IRAs) reserved for long-term care costs, as possible approaches to be considered. Some have suggested that cash accumulation instruments are perhaps most appropriate when there is a very high probability that a person will need a service at some point in time and when the costs of the service are not beyond the means of a person's life-time savings capacity. 42/ Home care services might be a more likely candidate for this form of financing than a long nursing home stay.

It should be noted that while insurers remain reluctant to enter the market for long-term care insurance, States, faced with mounting Medicaid nursing home

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41/ Meiners, Mark and Gordon Trapnell. Long-Term Care Insurance: Premium Estimates for Prototype Policies. Medical Care, v. 22, no. 10, Oct. 1984.

42/ Increasing Private Financing of Long-Term Care: Opportunities for Collaborative Action. SRI International, Aug. 1985. p. 10.

expenditures, are expressing increasing interest in having such coverage more widely available. According to the American Health Care Association, which represents nearly 8,000 nursing homes in the country and which is a leading advocate of private long-term care insurance, 24 States are currently involved in some activity related to options for enhancing private insurance for long-term care. 43/ Legislatures in a number of States have introduced bills that would mandate long-term care insurance coverage for group policies sold in the State. In addition, the National Association of Insurance Commissioners currently has underway a study group to assist State insurance commissioners in evaluating the increasing number of requests by insurers to establish policies.

B. Life Care or Continuing Care Retirement Communities 44/

One long-term care living arrangement available for financing long-term care services for a limited but potentially growing number of elderly persons is the life care community. Life care, also called continuing care retirement communities, are organizations, usually situated on a campus-like setting, established to provide housing, meals, housekeeping, and social activities, to older persons for the duration of their lives. In addition to these basic services, life care communities provide a range of long term care services offered on the grounds of the facility.

The distinguishing characteristic about life care communities is the guarantee that residents will be provided with a range of services as long as they are residents of the community. Rights and obligations of the resident and the

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43/ Lewin, Marion Ein. Reported in preliminary research findings on private insurance for long-term care. American Enterprise Institute, forthcoming.

44/ Portions of this section were drawn from a forthcoming CRS report on life care communities by Evelyn Howard.

community are defined under the [illegible] of a life care contract. The life care contract sets forth the [illegible] received by the resident in exchange for financial payments, in[illegible] fees and monthly charges. Because the life care contract is [illegible] financial protection against the future cost of long-term care [illegible], it may be viewed in part as a form of insurance.

Long-term care se[illegible] life care community may include skilled and intermediate [illegible] personal care, and other health care services such as home nurse [illegible] physical, occupational, or speech therapy. Life care communities may differ in the amount of pre-paid nursing care offered under the terms of the contract. Acute care and hospital care are not provided, and some communities may require the resident to share in the cost of health/long-term care services they receive from the community. Residents continue to use Medicare and/or private insurance plans to cover the costs of acute and long-term care services.

Generally residents who enter life care communities are relatively healthy but as their health/long-term care needs increase, they are provided with increased services as stipulated under the terms of the life care contract.

The number of life care communities is currently very small. Two major studies of communities have provided a range of estimates of the numbers of communities--from about 300 to 600, depending upon the definition used. It is estimated that there are at least 90,000 persons residing in nearly 300 such facilities. 45/ According to the American Association of Retired Persons, the

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45/ These estimates are from the following sources. A 1984 study, Continuing Care Retirement Communities: An Empirical, Financial and Legal Analysis [by] Howard E. Winklevoss and Alwyn V. Powell estimated that there were about 275 life care communities serving about 90,000 elderly persons. Another survey of the life care industry in 1984 by Laventhol and Horwath, estimated about 600 communities.

number of life care [illegible] years and is expected to more than double in this [illegible] care facilities in existence are operated by [illegible] especially religious organizations, alth[illegible] on the part of corporations in [illegible]

In order to [illegible] resident is required to pay a lump sum [illegible] thereafter which are usually adjusted for [illegible] size and type of living unit (e.g., studio, [illegible] apartment). In addition, fees are based on some actuarial [illegible] life expectancy rates and projected future health care needs.

Some analysts have observed that the entrance and monthly fees may make the life care community option inaccessible to large numbers of elderly. A 1984 study by Laventhol and Horwath of 600 communities found that the range of entrance fees was between $4,000 to over $100,000 depending upon a number of factors, such as location, size of living unit, and age of facility. 47/ Some analysts, however, dispute the claim that life care is only for the relatively well-off elderly. A study of communities by Winklevoss and Powell indicates that although the range of entrance fees is wide, the average fee is moderate. According to this survey, the average entrance fee for 275 communities in 1981

46/ American Association of Retired Persons. National Continuing Care Directory, edited by Ann Trueblood Raper. Washington, D.C., 1984. p. 5.

47/ Laventhol and Horwath. Life Care Industry, 1984, Philadelphia, Pa., p. 7. This report makes a distinction between facilities which are "principally life care facilities" and those which are "oriented toward nursing care." The former refers to facilities where there are two or more apartments per nursing care bed, and the latter refers to facilities where there are fewer than two apartments per nursing care bed. The range of fees cited here include both types.

was about $35,000 for one person and $39,000 for two persons, with average monthly payments of $562 and $815, respectively. 48/

Analysts have pointed out that the life care concept can be viewed as a m of long-term care insurance in that residents pool their resources and are the risk of future costs of long-term care services. A portion of the en- ance fees and monthly fees paid by all residents is used by the community to for the health and long-term care costs of a small number of residents need- g more extensive care at any given time. Because only a small number of resi- nts would be expected to need intensive services at a given time, the fees ould be considered like insurance premiums paid by the entire group but used by only a small group at a given time. In some cases, participation in a life care community may be viewed as a form of income redistribution when some portion of the fees paid by all residents are used to subsidize the costs of residents who can no longer afford to pay for their care. 49/

Supporters of life care communities indicate that there are a number of advantages in this mode of long-term care. Life care communities offer continuous, and in large part pre-paid health and supportive care in a protected setting with personal and financial protection against the costs of future health/long-term care needs. Residence in such a community may offer increased opportunities for residents to maintain their relatively healthy status upon entry since professional oversight is available on a regular basis, as compared to completely independent living in the community where older persons may not actively seek health promotion opportunities. Residence in a protective community which offers a range of care situations may allay the fears that many elderly face of

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48/ Winklevoss and Powell, p. 12.

49/ Winklevoss and Powell, p. 13.

making a sharp transition from their homes to permanent residence in a nursing home when they become suddenly disabled. The pooling of health and long-term care risks may reduce the uncertainties of future costs of care, and the care provided under the terms of the life care contract can supplement coverage of acute care provided by Medicare and private health insurance.

While life care communities may offer an option to some elderly, and even increasing numbers in the decades to come, they may not be able to serve a large proportion of the elderly population in general. Life care is not an option for the poor elderly or those with relatively intense pre-existing health/long-term care needs. The idea of signing over a large portion of accumulated assets in one lump sum to an organization in return for protection against future costs may not be acceptable to large numbers of elderly persons. Turning over assets in such a way may eliminate inheritances for children.

While some elderly may not be able to afford the relatively hefty entrance fees, analysts have pointed out that the equity older persons have in their homes may be employed for this purpose. The proportion of elderly persons owning their homes is large and they have substantial equity as a result. Of the 17.7 million households headed by older persons in 1983, 75 percent were owners. In 1980, about 84 percent of older home owners owned their homes free and clear, and in 1981 the median value of homes owned by the elderly was $44,300. 50/ One study points out that the high level of net home equity held by the elderly is not held only by those with higher income. About 63 percent of all elderly poor are homeowners, with 22 percent of the poor having more than $50,000 in

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50/ American Association of Retired Persons and the Administration on Aging. A Profile of Older Americans: 1984. p. 11.

net home equity. 51/ Other analysts indicate that because future generations of elderly will be better off than those of the past, the elderly may be in more advantaged positions to afford this kind of care in the future. Inflation adjusted retirement income under Social Security combined with private pensions and with IRA income may make the inflation adjusted monthly fees associated with life care communities payable by increased numbers of future generations of elderly.

Experience with life care communities is limited as are data about their effect on costs of organizing an integrated, pre-paid approach to long-term care service delivery. While it has offered an attractive option to a small number of elderly persons in the past, there have been problems. Some communities have experienced financial problems due in part to poor actuarial assumptions about the projected longevity of residents and their future health care needs, resulting in depletion of funds to cover costs. In view of these considerations, there has been interest on the part of Federal and State officials in more oversight and regulation over the development of these facilities in the interest of consumer protection. 52/

51/ Jacobs, Bruce and William Weissert. Home Equity Financing of Long-Term Care for the Elderly. Long Term Care Financing and Delivery Systems: Explaining Some Alternatives. Conference Proceedings. Health Care Financing Administration, Department of Health and Human Services. Washington, D.C. Jan. 1984. p. 83.

52/ In 1978, the Federal Trade Commission began investigating management and marketing practices of some life care communities. See U.S. Senate Special Community on Aging, Life Care Communities: Promises and Problems. S. Hrg. 98-276, Washington, D.C. May 25, 1983. As of August 1985, 13 States have enacted statutes to regulate life care communities.

C. Home Equity Conversion

The search for alternative approaches to long-term care services has led some researchers to analyze the feasibility of using the single largest asset most older persons have--the equity in their home. As pointed out in the previous section, about 75 percent of elderly headed households are owner occupied, and in 1980 about 84 percent of owners had no mortgage debt. The overall homeownership equity held by elderly is substantial. It is estimated that the total equity held by elderly homeowners with no mortgage debt is about $548 billion. This figure may underestimate the total equity available to the elderly since elderly homeowners with some remaining mortgage debt are not included. 53/ Some observers believe that, if converted into a source of cash, homeowner equity could be a tangible means of financing long-term care services for some elderly who are "house rich, but cash poor."

There are two major types of mortgage instruments which may be used to convert equity into income: reverse mortgages, and sale/leaseback contracts. 54/

- Under the reverse mortgage, the homeowner enters into a loan agreement with a financial institution which uses the property as security for the loan. The older person retains ownership rights to the home, receives a regular stream of income based on the loan, and accumulates a debt on the loan amount. The loan may be calculated so as not to exceed some proportion of the property value. When the loan becomes due the owner has the option to convert the debt into a regular first or second mortgage, to sell the property to pay off the debt, or obtain a new reverse mortgage. The time period for the

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53/ U.S. Congress. Senate. Special Committee on Aging. House Select Committee on Aging. Home Equity Conversion. Issues and Options for the Elderly Homeowner. Testimony of Kenneth Beirne, General Deputy Assistant Secretary for Policy Development and Research, Department of Housing and Urban Development. Briefing Document. House Pub. 99-513. Jan. 28, 1985. Washington, D.C. p. 58.

54/ Reverse mortgages are also sometimes described as "reverse annuity mortgages" or "loan plans." For further information, see Converting Home Equity Into Income for the Elderly: Issues and Options, by B. Ellington Foote, CRS Report No. 84-42. Apr. 5, 1984.

reverse mortagage may range from 7-10 years or for the remainder of the individuals lifetime depending upon the terms of the contract.

- Under the sale/leaseback contract, the homeowner sells the equity in the home but retains the right to reside there, usually for life. The buyer of the equity provides the elderly homeowner with a down payment and pays the balance in regular monthly installments. The seller, then, in effect becomes a renter of the home which he/she formally owned.

In one extensive analysis of the potential for application of homeowner equity toward payment of long-term care expenses, researchers concluded that there is evidence that a large proportion of older persons could use some of their home equity to finance long-term care needs. This analysis showed that about one-third to one-half of all elderly homeowners at high risk of need for home care could finance a portion of home care needs out of homeowner equity. The analysis also found that homeowner equity could be used to pay for long-term care insurance premiums as well as for nursing home care. 55/ Another analysis which reviewed the potential for use of homeowner equity to purchase private long-term care insurance showed that home equity conversion could increase the ability of some elderly homeowners to pay for long-term care insurance, but concluded that reverse annuity mortgages and sale/leaseback arrangements do not easily provide for long-term care financing. Since these arrangements provide for payments to individuals for longer periods of time than usually needed to finance certain long-term care expenses, they may not have wide application for certain expenses requiring lump sums of cash over a short period of time. This report suggested that home equity conversion could be more

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55/ Jacobs, Bruce and William Weissert. Home Equity Financing of Long-Term Care for the Elderly. In Long Term Care Financing and Delivery Systems: Exploring Some Alternatives, Conference Proceedings, Health Care Financing Administration, Department of Health and Human Services. Washington, D.C. Jan. 24, 1984. It should be noted that these findings were based on a model of probability of using home equity for this purpose, not on actual experience as to application of equity toward long-term care expenses.

useful if financial institutions permitted owners to use their homes as lines of credit, as necessary, to pay for long-term care expenses. 56/

While the idea of using home equity for payments of on-going expenses of the elderly has appeared in the literature for a number of years, the actual number of home equity conversion contracts is very limited (estimates range from 300 to 400 contracts at most). Lenders in only a handful of States have offered home equity loans and these loans may not be made on a regular basis. 57/ Therefore, the actual experience is relatively meager and its specific application to long-term care may be tentative.

Thus far, there appears to be a lack of consumer demand. A number of obstacles have been cited as barriers to the future development of these arrangements. Many of the elderly may be reluctant to enter into these agreements because they wish to pass on some inheritance to their heirs. Also, even if this strategy were more widely available, some question whether the elderly would actually use the funds to pay for long-term care services. Other elderly may not participate because they may feel that services available from public sources will be decreased if they use their home equity. Also, they may feel that if they outlive their equity they may be forced to move. A number of other issues have been raised, including possible depreciation of homes, and concern that the elderly would not receive fair market value for their homes

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56/ ICF Incorporated. Private Financing of Long-Term Care: Current Methods and Resources. Phase II. Submitted to the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, Jan. 1985. pp. 25-26.

57/ According to an information paper of the U.S. Senate Special Committee on Aging, lenders in the following States have offered loans: Arizona, California, Maine, Minnesota, New Jersey, Ohio, Pennsylvania, and Wisconsin. See U.S. Congress. Senate. Special Committee on Aging. Turning Home Equity into Income for Older Homeowners: An Information Paper. S. Rept. 98-216. July 1984. p. 12.

or that the lenders may default on the loans. These issues would require consumer protection measures.

There has been reluctance on the part of financial institutions to offer these instruments, particularly due to the current lack of mortgage insurance on the loans. Also, if the elderly homeowner lives beyond his/her equity, lending institutions may lose money because they may be reluctant to evict an elderly homeowner when the equity is exhausted. Finally, institutions may not want to enter into agreements in cases where the home is not expected to appreciate.

Other issues with respect to the tax implications of home equity conversions remain to be resolved. According to the Department of Housing and Urban Development (HUD), the status of sale/leaseback arrangements under the Internal Revenue Services (IRS) code is unclear. Questions in need of resolution include the right of the seller-lessee to take advantage of the one-time homeowner capital gains exclusion, and the ability of the purchaser-lessor to depreciate the rental property like other rental property. 58/

In 1983, Congress required HUD to develop a report evaluating the use of home equity conversion mortgages for the elderly, including the impact on financial institutions, the potential for acceptance of this concept in the private market, and any recommendations on the establishment of a Federal insurance program for insuring home equity mortgages. 59/

While home equity conversion is not extensively available, such arrangements may be attractive to some elderly for targeted long-term care expenses

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58/ U.S. Congress. Senate Special Committee on Aging and House Select Committee on Aging, Home Equity Conversion: Issues and Options for the Elderly Homeowner. Testimony of Kenneth Beirne, p. 59.

59/ This provision was included as part of P.L. 98-181, enacted Nov. 30, 1983. The report was due in Nov. 1984. As of Oct. 1985 the report is receiving HUD clearance.

if the market became sufficiently developed and loans were devised to be responsive to individual needs. Conversion of home equity into cash to be applied toward the down payment for life care facilities was discussed above. Conversion of home equity to remain in one's own home may be more attractive in the long run than using equity to finance a life care facility down payment. Because this option allows house rich, but cash poor elderly to remain in their own homes by drawing upon a ready flow of funds, it may ultimately appeal to many more persons than life care. It may particularly appeal to those without heirs who would benefit from the sale of the home upon the death of the homeowner. Advocates of this concept indicate that this strategy could generate a significant amount of funds which, if directed toward payment of long-term care services paid for by public sector programs, could reduce pressure on these programs.

V. ISSUES TO BE CONSIDERED IN FUTURE PROSPECTS FOR LONG-TERM CARE

In the past, debate on Federal long-term care policy has focused on a number of issues which policy-makers still seek to resolve: how to offer more consistent and adequate protection for long-term care expenses; how to strike a balance between institutional and community-based care; and whether community-based care is more cost-effective than institutional care. Whereas in the past these issues were discussed principally in the context of proposals to reform Federal programs of support for long-term care, today questions arising from these issues are applied as well to a new dimension of the debate: the extent to which private sector alternatives, such as private insurance, life care communities, and home equity conversion, can improve the elderly's ability to finance the long-term care services they need and want. Although the debate may have widened to include private sector approaches, it is likely that reform of current Federal benefit programs will continue to be an area of consideration due to the large Federal investment in long-term care as well as the large numbers of elderly who depend upon these programs for assistance. Some of the questions to be reviewed in the future may include the following:

- What are appropriate roles for public programs and private sector options to play in the financing of long-term care? Can comprehensive long-term care coverage be provided without public mandate and/or subsidy? For example, the health insurance industry has been reluctant to offer comprehensive long-term care coverage, suggesting that adverse selection and induced demand for services will result in an insufficient pool of premium income to cover anticipated expenditures. What measures are necessary to obtain an adequate population base for long-term care insurance coverage that is affordable? Is some kind of public mandate required?
- Even if the economic status of future generations of the elderly improves significantly, it is likely that they will continue to have differentiated needs and abilities to pay for long-term care? How should public programs and private sector options respond to the needs of a diverse population? How can they most suitably complement each other?

- Can private sector alternatives begin to improve the ability of the elderly to finance their own long-term care expenses without reform of Federal programs of support? Currently many elderly persons have no other choice but to incur sizable out-of-pocket expenditures for long-term care, depleting their incomes and assets to become eligible for Medicaid's nursing home benefit. For these persons, Medicaid offers protection of the last resort. Others have pointed out that Medicaid is used by far more than a low-income population and that many middle income individuals are transferring their assets to relatives in order to qualify for Medicaid's nursing home benefit before actually incurring catastrophic long-term care expenditures. The Health Insurance Association of America has suggested reducing Medicaid's involvement in the financing of nursing home care so that fewer middle income individuals can use the program as a viable option for their long-term care needs. However, little is known about the number of persons who actually transfer assets in order to qualify for Medicaid's nursing home benefit. Out-of-pocket expenditures for nursing home care, on the other hand, amount to half of total national expenditures and are this high because private sector coverage is very limited and elderly persons must deplete their incomes and assets. Given these considerations, how should reform of public programs proceed?

- Public programs and limited private insurance currently provide more support for institutional forms of long-term care than for community-based care. Uncertainty about the costs of expanded community-based care has inhibited the broadening of coverage for these services. There appears to be consensus, however, that regardless of the cost of community-based services as compared to institutional care, community care is the more desirable option for most persons with chronic disabilities. Despite the prevalence of chronic conditions, most older persons are in reasonably good health and most chronically ill persons want to be as self-sufficient and independent as possible. There is also substantial evidence that family members would prefer to continue providing support services if some form of assistance were available to make their continued efforts possible. What kinds of controls must be in place for home care coverage to be more extensively included in public or private financing programs for long-term care? Can expanded home care coverage be included only in a managed care setting much as a social/health maintenance organization or life care community?

[Whereupon, at 1:10 p.m., the subcommittee was adjourned subject to the call of the Chair.]

ALZHEIMER'S DISEASE AND RELATED DISORDERS

MONDAY, JANUARY 27, 1986

HOUSE OF REPRESENTATIVES,
COMMITTEE ON ENERGY AND COMMERCE,
SUBCOMMITTEE ON HEALTH AND ENVIRONMENT,
Palm Harbor, FL.

The subcommittee met, pursuant to call, at 10 a.m., in the chapel, St. Mark Village, 2655 Nebraska Avenue, Palm Harbor, FL, Hon. Henry A. Waxman (chairman) presiding.

Mr. **WAXMAN**. The meeting will please come to order.

I would like to welcome everyone here today for this official hearing of the House Subcommittee on Health and the Environment, which is a subcommittee of the Energy and Commerce Committee. I wish to thank Congressman Bilirakis for inviting us to this hearing on Alzheimer's disease.

Today's hearing is on aging and Alzheimer's disease, on support groups and coping, and on families and frustration. Two and a half years ago our subcommittee held its first hearing on Alzheimer's disease and related disorders. We heard from families and physicians about the tragic results of the disease. And we heard from researchers and caretakers about lack of knowledge regarding the cause, cure, or costs. We learned what was being done for patients and what work remained. We came away from that hearing convinced of the magnitude of the problem and committed to seeking solutions.

Two and a half years later, much of the information provided at that Washington hearing has become common knowledge. Symptoms of the condition have become well known: forgetfulness, disorientation, and restlessness. And so have its consequences: Alzheimer's disease means progressive disability for victims and despair, and in many cases, financial destruction for families as they watch their loved one slip away.

Some progress has been made since the subcommittee first met on the issue. Because of our efforts, the National Institutes of Health are funding research projects at 10 Alzheimer's disease centers throughout the country. In years ahead this research could lead to the discovery of both the cause and cure of Alzheimer's.

Yet, while research on causes and cures continues, the clinical needs of current patients and their families cannot be forgotten. For them, the causes and potential cures for this devastating disease are irrelevant. They need help now.

So while we await the research breakthroughs, work must still be done to secure funding for services for Alzheimer's disease victims and their families. Most of America's 2 million Alzheimer's patients and their families simply cannot pay for the services that are required.

And little help is available. Like all long-term care services, those to address the needs of Alzheimer's patients are not adequately covered by either private or public programs.

For those who can afford private health insurance, limited services are given. Public financing offers almost nothing.

Medicare does not pay. Medicaid requires impoverishment before benefits are available. And social service programs continue to be slashed. The frail and vulnerable, the confused and disoriented, are left behind to cope as best they can.

Such callousness is wrong. Such policies are wrong. It is wrong to restrict coverage for services that are appropriate. It is wrong to cut the few programs that do offer some assistance. And it is wrong to force those who need help to go broke in order to get it.

It is frustrating for all of us—victims, families and policymakers alike—that more progress has not been achieved in resolving these issues over the last 2½ years. So we come here today with a renewed sense of the problems of an even greater commitment to find the answers. We need your help to do that—those of you who are going to participate in this hearing today—and we need it now more than ever before.

I want to call upon my colleague, Mr. Bilirakis, to make an opening statement at this hearing. But I first of all, I want to make a note of the fact that we have a statement submitted for the record by Congressman Roybal, who is the chairman of the Select Committee on Aging, and another one by Congressman Pepper, who is the former chairman of the Select Committee on Aging. And without objection we will enter their statements in the record at this time.

[Statements of Representatives Roybal and Pepper follow:]

STATEMENT OF EDWARD R. ROYBAL, CHAIRMAN, HOUSE SELECT COMMITTEE ON AGING

It is with deepest regret that I am unable to participate in today's most critical hearing as I have been forced to return home to Los Angeles. However, I want you to know that the fight against Alzheimer's disease and the tremendous burden it places on millions of Americans is one to which I am deeply and personally committed. Unfortunately, it is a fight we have only just begun.

Fortunately, the fight has a major ally in the person of the chairman of the subcommittee on health and the environment, Henry Waxman. I can assure you that he and I have much in common, whether it be a commitment to the health of all Americans or the common home base of Los Angeles. Today we share another common bond—a commitment to helping the victims of Alzheimer's disease.

In the difficult battles ahead, we are truly fortunate to have another strong ally and your Representative, Mike Bilirakis. Mike is a long-time friend, former member of the Aging Committee, and a committed partner in of our effort against Alzheimer's.

How to care for the victims of Alzheimer's disease and related disorders is an important issue just because so many people suffer from these diseases. The issue becomes even more important when you consider that the cost of their care to families and the Nation is more than 20 billion dollars annually. Though the financial cost is great, the greatest tragedy is still the human cost for the victims and their families.

Today you will be hearing testimony from those who most immediately suffer the pain of caring for a father, a mother, or a spouse who suffers from these dreaded diseases. Every day these family members deserve our deepest respect and appreciation for having shouldered this heavy burden. Today they deserve our admiration again as they share their experiences in caring for a family member afflicted by these deadly diseases.

However, Congress must go beyond simply understanding this enormous tragedy to take immediate, additional action. I am convinced that Alzheimer's is an exceptional disease which requires exceptional handling by the Congress this year. In 1985, we spent only 43 million dollars on Alzheimer's related research. With the exception of Medicaid, virtually nothing is being done to help the victim or the families.

Though 1986 is known as the year of "Gramm-Rudman," Alzheimer's disease clearly demands special attention. In my own "CARE" Bill (H.R. 2280), I am proposing a substantial step forward in funding for research and a beginning step in support for the families. Fortunately, there are also other important pieces of Alzheimer's legislation which should be considered. One is a bill by Mike Bilirakis. Another bill is by Representative Claude Pepper, my esteemed predecessor as chairman of the Aging Committee and the current chairman of the Rules Committee. Both of their bills deserve support as well.

Again I want to express my great appreciation to Chairman Waxman for holding this hearing today. I look forward to his return to Washington where all of us can assist him in his effort to enact a significant and supportive piece of Alzheimer's legislation.

Statement of Hon. Claude Pepper, Chairman, Subcommittee on Health and Long-Term Care, House Select Committee on Aging

Good morning, Mr. Chairman, Mr. Bilirakis, and other guests. I wish I would be with you for your hearing on one of the most important issues facing today's elderly, and those who will grow old in the future, Alzheimer's disease. I want to commend the subcommittee on Health and the Environment for holding this hearing today. I know it will be an interesting and informative session.

I also applaud my distinguished colleague from Florida, Mr. Bilirakis, who is an active member of the Aging Committee, too. He has devoted considerable energy to seeking relief for Alzheimer's victims and their families.

Alzheimer's disease was barely known outside medical circles 20 years ago, but today we recognize it as one of the cruelest and most widespread of illnesses. By progressively causing its victims' brains to degenerate, Alzheimer's Disease depersonalizes them, robbing them of their humanity, their emotions, and their ability to think.

I'm pleased to say that Alzheimer's research projects are being conducted in some of the greatest medical and scientific institutions in America. Of course, we have a long way to go but progress can be seen. I do hope with all my heart that the cure for that monster, Alzheimer's disease, will be found in the near future.

In the meantime, an estimated 1.2 to 4 million Americans currently suffering with Alzheimer's disease cry out for help now! What can we do to alleviate the sorrow and suffering of those individuals and their families?

Nowhere in our society are individuals left to unassisted and exposed to the hazards of a catastrophic illness as are the victims of Alzheimer's disease. Federal coverage under Medicare and veterans' health programs is minimal. Private assistance and other health insurance policies are almost non-existent.

Mr. Bilirakis has introduced two bills to improve the situation, H.R. 66 and H.R. 67. These would create family support groups for Alzheimer's victims and establish a Medicare demonstration project for treatment of Alzheimer's.

I share his goals and have myself introduced legislation, H.R. 524, to create 20 regional centers for the treatment of Alzheimer's disease and similar disorders.

I know that Mr. Waxman and Mr. Bilirakis believe, as I do, that the time has come to recognize and begin to address the enormous problem of Alzheimer's disease.

I look forward to reading the proceedings of this important hearing.

Mr. **Waxman**. The reason we are here is because of Congressman Bilirakis, who has shown such great leadership in this whole area of Alzheimer's disease and aging problems. I think he and I are among the few members of both the Select Committee on Aging and the health legislative committee which is our Health Subcommittee.

The Aging Committee is looking at options, is looking at ways to deal with this problem, and is giving us ideas. But when legislation is acted upon, it will have to go through our committee. Congressman Bilirakis has shown leadership and commitment to trying to find some solutions, some answers to this very difficult problem.

He has introduced legislation which is before our committee and I am pleased to join with him in attending this field hearing today so that we can develop a record of the testimony that we'll be able to share with our colleagues in Washington as we try to move legislation along.

Mr. Bilirakis.

Mr. **Bilirakis**. Thank you Mr. Chairman. Ladies and gentlemen, good morning.

I wish to express my sincere gratitude and appreciation to my distinguished chairman, Congressman Henry Waxman of California, for agreeing to come to our district so that we can discuss the issues of long term care and Alzheimer's disease. I want to commend my chairman, for without the compassion, concern and foresight that he has exhibited progress would be a long time coming.

I also want to take a moment to thank our generous hosts here at St. Mark and this morning's witnesses. They have all demonstrated a great deal of concern and commitment. And I would also like to thank Mr. Joe Kutner and Mr. Ed Geasa for their invaluable assistance.

Mr. Chairman, ladies and gentlemen, let us begin by looking at the facts. Long-term care refers to health and social services that are provided to the chronically ill and functionally impaired. An estimated 6.6 million Americans age 65 and older need long-term care today. What is more, as the baby boom generation ages and individuals live longer the desire and need for long-term care will become even greater.

In fact, it is projected that the number of elderly in need of long-term care will increase to 9.3 million by the year 2000, to 12.9 million by 2020 and to almost 19 million by 2040. As individuals live longer they become more susceptible to developing chronic health conditions that require medical assistance over extended periods of time.

Care for debilitating chronic conditions, or long-term care, is not covered by Medicare. Long-term care is expensive and can rapidly deplete a lifetime savings. In fact, studies conclude that nearly two-thirds of the persons who enter nursing homes become impoverished in just over 3 months.

This statistic is, I am sure you will agree, truly shocking and frightening. Long-term care financing is one of the most serious challenges confronting our society. The elderly and their families have few alternatives for reducing their out-of-pocket expenditures for long-term care.

Most elderly lack the financial resources to pay for such care and private insurance is virtually nonexistent. Medicaid, which pays for the health care of the financially needy, has become the only mechanism for financing long-term care. The Medicaid program, however, primarily covers services rendered in institutional settings, rather than home or community-based services.

Furthermore, it poses an additional problem in that one must become impoverished, as our chairman has indicated, in order to become eligible. Yet, unless financing mechanisms change, more pressure will be brought to bear on the program. Medicaid alone cannot shoulder the burden of long-term care. The demand for alternatives will, no doubt, continue to grow as the population continues to age.

Solving the problems of financing long-term care and efficiently providing long-term care services will require innovation and the cooperation of everyone affected: Government, health care providers, health insurance companies and consumers.

Among the debilitating health conditions requiring long-term care today, as you know, is Alzheimer's disease, and it has certainly got to rank among the most prevalent and severe.

The fact is that this deadly mental disorder currently claims 2½ million Americans and has the sad distinction of being the fourth leading cause of death among our elderly. The deadly illness has been known to take as long as 20 years to run its course, eventually leaving its victim unable to recognize his family or perform even the most basic daily functions.

As many of you are probably aware, I have had a great interest in the area of Alzheimer's disease since first being elected to Congress and have introduced the Alzheimer's relief package in order to assist the victims of Alzheimer's disease and their families. The package consists of two bills—H.R. 66 and H.R. 67—which are intended to provide emotional and financial assistance to the millions of Alzheimer's victims and the affected families.

I am pleased to report that H.R. 66, which calls for the Secretary of Health and Human Services, through NIMH and the Administration on Aging, to promote the establishment of a national network of family support groups in university medical centers and in other appropriate health care faclities receiving Federal funds, has been passed by the Energy and Commerce Committee, thanks to the help of the chairman, Mr. Waxman, and is awaiting passage by the full House.

The second bill in the Alzheimer's relief package, H.R. 67, is the Alzheimer's demonstration projects for Medicare bill. The purpose of this legislation is to create 10, 1-year demonstration projects to determine the feasibility of Medicare assistance for Alzheimer's disease.

The need, my friends and neighbors, for financial assistance for victims of Alzheimer's disease and their families cannot be stressed strongly enough. The exhorbitant costs of nursing home care today, some as high as $16,000 or better a year, coupled with the lengthy duration of this illness clearly illustrates how Alzheimer's disease can easily financially devastate entire families.

Hearings such as this one are important in that they bring together the different parties, legislators, health care providers, and so forth, that are in a position to effect changes in current policy. I am hopeful that today's meeting of our Health and Environment Subcommittee will help us find some solutions to addressing the long term care needs of our elderly.

Enough from me, however. I am certain that everyone is anxiously awaiting the testimony of our distinguished witnesses, so I will not delay any longer. Thank you, Mr. Chairman.

Mr. **Waxman**. Thank you, Mr. Bilirakis. We have a lengthy list of people that we want to hear from today and, after that, Mr. Bilirakis has asked us if we would hold the record open and have an opportunity for people to get up and make any comments they wish, who are here in the audience.

Because we have a long schedule of witnesses we are going to have to ask each person who is going to testify to be a few minutes, 2, 3, 4 minutes, no more than 5 minutes in length for their testimony.

We will have a chance for questions and answers and then complete the hearing today. I might just mention the fact that Mr. Bilirakis mentioned the bill he introduced which would set up the Alzheimer's family support groups in institutions.

It has passed our committee and, as a matter of fact, one of the reasons we will have to curtail the hearing this afternoon is we have to bring that bill on the floor this week. I did not know if you were aware of that, but we are going to bring it to the House floor and we hope it will pass then through the House and get the Senate to go along with it as well.

Our first panel is a group of very special people. Each of them has felt the pain, the frustration, that accompanies Alzheimer's because each one of them has had to live with or take care of a victim of this disease. They all have first hand knowledge of what this disease does to individuals and to families.

I would like to ask them now to come up to our witness table and simply tell us a little about their experience with Alzheimer's. Mrs. DeeAnn Foster comes from Clearwater. Mr. James Kelly is from Palm Harbor. From Tampa, we'll be hearing from Mrs. Ada Pyles and Mrs. Della Cury. And finally, we have Mr. Max Patton from Safety Harbor.

Would you please come forward and take a seat? We would appreciate it. I want to thank each one of you for coming to our hearing today. It is important, as you are aware, but I want to emphasize it, that we as Congressmen hear about your personal experiences. It is important not just for the two of us, but for all of those members of Congress that we are going to share your testimony with. Your thoughts and comments are really very helpful and they are going to be helpful in trying to shape Federal health policies that will meet the needs in the most cost effective way.

I know that some of you have prepared statements for today's hearing. Those statements will be put into the record.

For now, what we want each of you to do is to take a few minutes to summarize your thoughts and then we will have some questions for you.

Mrs. Foster, why don't we start with you. If you'll pass the mike—I hope it will reach, if not maybe we can trade seats during the time of testimony. Your full statements are going to be part of the record so if you have a written statement we will have that all in the record.

STATEMENTS OF DEEANN FOSTER, CLEARWATER; JAMES G. KELLY, PALM HARBOR; ADA PYLES, TAMPA; MAX PATTON, SAFETY HARBOR; AND DELLA CURY, TAMPA

Ms. Foster. My name is DeeAnn Foster. I am a professional guardian and member of the Guardian Association with Pinellas County. At this time I am taking care of 22 wards, 6 of which are confirmed Alzheimer's disease.

The first thing I do when I take a case, Health & Investigation has usually investigated the case and they will very often give me an idea that Alzheimer's is suspected. I try at this time to get CAT scans so that we actually know what we are dealing with. It is very important, right at the beginning, to know if we are dealing with Alzheimer's because it will affect every decision being made in behalf of this ward.

I have been helped a great deal by Community Care for the Elderly which is a State and private donation. I am often able to keep the wards in their own homes for a period of time with the help of these agencies. Meals on Wheels is often a great help. However, Alzheimer's patients are not easy to work with.

They are belligerent and very frightful people. As I have found them to have been hardworking, usually in one career choice their whole lives, have contributed generously to society and, therefore, their pride and independence is very important to them.

So it is a very hard thing to get them to accept outside help. Among—all of mine are beyond the 65 year age limit usually by the time I get them, so they have had the disease for many, many years. Placing them is a big problem. Few congregate living facilities are prepared to deal with the specialized care of the Alzheimer's patient.

Even our nursing homes have trouble dealing with a hands-on situation. Where there is money available we put extra help in with them. For instance, yesterday morning a man in a nursing home, we had to insert a food tube into his throat because he suddenly can no longer remember to swallow. This type of care cannot be provided unless we have outside help.

At this point it is all private and as long as the funds will last we can get them whatever care they need and I intend that their money be used to give them whatever they need until it runs out. All six patients have had a good retirement. They are all looking at, if they live another 2 or 3 years, to be back on public aid. Thank you.

[The prepared statement of Ms. Foster follows:]

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As a professional guardian, it is interesting to note that 20% of my wards have a confirmed C.A.T. Scan diagnosis Alzheimer's Disease.

When I was asked to be guardian in each of these cases, Alzheimer's was suspected but not diagnosed. It is important to know as soon as possible if the patient has Alzheimer's Disease as it will affect all discussions made in the ward's behalf.

Charlie R. is a childless, 85-year old Caucasian man living with his 82-year old wife in a nursing home. When I accepted this case in May 1985, Charlie and Mary were living in a beautiful, well furnished mobile home in Clearwater, Florida.

They were helped by part-time aids through Community Care for the Elderly which is supported by the State and private donations. They were also helped by Meals on Wheels. Charlie was having periods of violence often forcing the aids out of the home. Mary, who suffers with Lukemia and Dementia, was weeping most of the time. Charlie would be found wandering often dragging Mary along the busy streets of Clearwater, sometimes appearing in public places demanding money. There were long periods of paranoia, and hallucinations were exhibited. Somewhere along the line their jewelry had disappeared. Anyone could have removed it from them in their state of confusion.

In August of 1985 it was necessary to place Charlie and Mary into an Adult Congregate Living Facility for 24-hour supervision. This proved unsatisfactory as Charlie could not be kept from wandering away, again dragging a weeping Mary along. There were also violent episodes usually occurring in the middle of the night. Before the onset of the disease, this had been a very happy and congenial marriage. The facility asked that Charlie and Mary be moved in September 1985 as they could no longer accept them as residents. Charlie was too upsetting to the other people in the home.

During Charlie's working years he was with Rochester, New York, Gas Company, working until retirement, saving and investing his money, and conscientiously preparing for retirement. When he and Mary retired to Florida, he secured their futures with a trust arrangement, and they enjoyed a social and prosperous retirement.

Charlie's first problems involved traffic accidents, and he reluctantly volunteered to give up his automobile. This is always a turning point in retirement, especially in Pinellas County where public transit is very limited. Since September 1985 Charlie and Mary have lived in a nursing home. Both have had to be in a hospital and are fast depleting their savings. In selecting a nursing home, great care was used to assure that when their money runs out, the facility accepts Medicade.

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As Charlie's disease progresses, more problems are encountered. His behavior is getting more out of control, medication is more expensive, and the violence towards his wife may soon force them to be separated, causing additional expenses. Another three years of life will force both partners of this marriage on to public assistance.

Sally W. is a childless, Caucasian 74-year old female living alone in her modest mobile home. She and her husband both held responsible jobs all of their working years. Her husband died a year ago leaving Sally without his pension. She cannot live within her Social Security income and pulls from savings, which are under $10,000. With the help of Community Care for the Elderly three times a week, and private visits twice daily, she is able to stay in her own home. This is a day-to-day state. Any day may bring the call that may force us to place her in a nursing home. An Adult Congregate Living Facility does not look like a viable alternative. Everything she owns will be sold. This will provide about a year as private pay in a nursing home. Then she would be placed on public assistance.

Sally has some days she cannot remember the names of very common things, such as chairs, telephones or even rooms. Other days she functions well, but medication and meals are increasingly becoming a problem to living alone. She will not accept Meals on Wheels.

If savings are used up, she is not eligible for Medicade assistance in her own home, as Social Security income falls over the limit but under what it takes to sustain her.

Harold F. is a 76-year old male Caucasian. He lost his wife to heart disease eight months ago. He has a generous estate including a home. In addition to Alzheimer's, he has just fallen and broken a hip.

Due to the fact that Harold's children are out-of-state, most of his personal property has been sold. The home is now being rented. He is severely depressed and needed private-duty nursing in the hospital, and we are continuing this in the nursing home. One of Harold's real problems is that he can't remember to chew or swallow food. Just this morning we have had to order a tube placed in his throat. We are hopeful that he will respond to this "hands on" care. It has worked well in one other case. At $70,00 a day for aid attendance plus the cost of nursing home care, even a generous estate will run out, and he can expect to end up on public aid. The kind of individual care that is needed by Alzheimer's patients does not seem covered as regular care by nursing homes.

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As you can see, each Alzheimer's case is as individual as the person himself.

From the professional guardian's viewpoint, when you accept a suspected Alzheimer's case, you realize they take special and additional time. I have never had an "easy" case. They are usually uncooperative, unreasonable and demand five times as much time as other wards. Placing them is always a problem, and most Adult Congregate Living Facilities are not equipped to deal with them. In working with Community Care for the Elderly, I have found transportation to be a major financial concern.

Alzheimer's patients are usually very intelligent, have had interesting careers, have contributed generously to society, and have lead productive lives. With Alzheimer's Disease, no amount of money is security.

Respectfully submitted,

DeeAnn Foster

DeeAnn Foster
Professional Guardian

Mr. **Waxman**. Thank you very much, Mrs. Foster.

Mr. Kelly.

STATEMENT OF JAMES G. KELLY

Mr. **Kelly**. I would like to introduce my testimony by reading the first paragraph of my prepared statement. When Julia—my wife Julia Kelly—first showed signs of personality change and forgetfulness in 1970, she was 55 years of age. It was a very gradual thing and not immediately recognized.

Inasmuch as we were both going through job-related problems I attributed these changes to emotional upset that would be alleviated by the passage of time. I would like to inject that Julia was a very bright individual, graduated from college at age 20, a very articulate and outgoing person.

It was not until the mid-1970's, after she was subjected to extensive tests, that her illness was diagnosed as Alzheimer's. Somewhere about this time she lost the ability to know the day of the week, tell time, cooking skills, interest in reading, ability to converse, et cetera. She avoided people, including close friends, preferring to sit alone in a darkened room.

Eventually I had to deny her the use of the car and restrict her to the home as best I could. When she did get out she frequently got lost in our neighborhood where she had resided for 30 years. Alzheimer's destroys the whole person. Too much is said about the memory. It is a serious thing but I found you could cope during the early stages with the memory problem.

The biggest thing I found that was hard to accept was the personality change—that was immediately noticed. I recognized that before I recognized the memory problem. I continued to work, for my own peace of mind, I worked until my 67th year. Fortunately, though, as a result of my job change I only worked 3 to 4 miles from home, I had good neighbors who watched over her.

If they saw her in the street, they would either get her back into the house or call me at work. We lived in a small community, we enjoyed our own police department and they all knew me, knew her, they would bring her to the house, call me at work.

Fortunately, I had an understanding company who recognized my necessity to run in and out, sometimes twice a day, sometimes maybe only three to four times a week. The task of trying to discipline myself was a hard thing to cope with.

I was behind the door when God gave out patience and just looking back in retrospect I am sort of proud of myself how I learned to cope with her for 10 years at home. I eventually moved to Florida because I had to get out of a large home. The stairs were very dangerous for her.

I had to turn off the gas at night. I had to turn off the water. I had to put locks on the refrigerator. All these things in order to control her. I put straps around my bureaus, dressers, anything where she could disrupt things. Alzheimer's victims are up 24 hours a day. They catnap, 10 minutes at a time.

When I moved to Florida I bought a small home here in Palm Harbor. I had to double lock all the doors. Of course, I had to go through the same exercise of turning off the range at night, turning off the water, and despite that I was exhausted and would fall asleep. Sometimes I would forget to lock the door and the next thing a neighbor would be bringing her home.

Sometimes I had to bathe her two or three times a day and while I was looking for a change of clothes she would get out of the house and many a time there was stark naked Julie running down the street. These things, you know, are a little humorous now that I look back but, believe me, living with it is hell on Earth.

[The prepared statement of Mr. Kelly follows:]

SUBJECT: Congressional Hearing on Alzheimer's Disease
PLACE: ST. Mark Village, Palm Harbor, FL
DATE: January 27, 1986
TESTIMONY BY: James G. Kelly
1659 E. Dorchester Court
Palm Harbor, FL 33563

My wife, Julia R. Kelly first showed signs of personality change and forgetfulness in 1970. She was 55 years old. It was a very gradual thing and not immediately recognized. In as much as we were both going through job related problems, I attributed these changes to emotional upset that would be alleviated by the passage of time. I would like to inject that Julie was a very bright individual, graduated from college at age 20. A very articulate and outgoing person.
It was not until the mid-seventies after she was subjected to extensive tests that her illness was diagnosed as Alzheimers. Somewhere about this time she lost her ability to tell time, cooking skills, interest in reading, ability to converse, etc. She avoided people, including close friends, preferring to sit alone in a dark room. Eventually, I had to deny her use of a car and restrict her to the house as best I could. When she did get out she frequently got lost in our neighborhood, where we resided for thirty years.

For my own peace of mind and a little diversion from house-hold chores and patient care I continued working until my sixty-seventh year. Although, Julie was affected with a terminal disease, her doctor continued to marvel at her otherwise good health and predicted that she had a long life ahead of her. I anticipated that the Alzheimers could progress to the point that I would no longer be able to cope with the situation and that I would be faced with the tremendous financial burden of nursing home care. In 1981 I recognized that our Long Island home was too large for me to physically maintain and too dangerous (stairs) for her.

After much deliberation I decided that I could best function in a warm area so I retired and moved to Florida. It proved to be the right decision.

Unfortunately, Julie continued to deteriorate rapidly and after a very serious accident at home I had to face reality, no alternative but to place her in a nursing facility.

Her life sustaining functions continued to be strong and the doctor reiterated a projection for many more years of life.

During the first few months that she was confined to the Nursing Center I was able to forecast what my assets would cover. I was shocked to learn that the quarter of a million dollar medical plan included in my retirement package contained an exclusion for those suffering from mental disorders. Using our basic estimate of $25,000/year plus 5% yearly escalation it was easy to see financial devastation on the horizon.

I attended Alzheimer's support group meetings sponsored by HRS. They were an excellent source of information and offered the opportunity to cry on one another's shoulder. It was during one of these meetings that I heard the greatest news and encouragement regarding financial matters. We were told by the speakers that those carrying a nursing home burden should investigate Medicaid, and that only the patient's assets were considered in making a determination as to eligibility. Here-to-fore I had been advised that a spouse was responsible for a partner's care. In my particular case the major percentage of assets were in my name. This was not the result of any planning or deliberate action on my part. It occured simply as a result of my wife's inability to make any decisions or to sign her name during the preceding six years.

I filed for Medicare. In support of this twelve (12) page application the Health and Rehabilitative Services requested complete financial disclosure of all our assets going back a few years prior to date of application. It was necessary to identify each individual asset, current status and if disposed of, how and when. This exercise required a considerable amount of effort and at times it could be difficult to show the continuity from one transaction to another.

I'm not suggesting that this request for supporting data was unreasonable. The people at HRS were very cooperative and understanding of all submissions I presented. Some of the clarifying data they requested was sometimes difficult to obtain from other sources.

Subsequently, Medicaid was approved for my wife. Unfortunately, or perhaps I should say fortunately, Julie died less than a month later.

STATEMENT OF ADA PYLES

Mr. **Waxman**. Mrs. Pyles.

Mrs. **Pyles**. My name is Ada Pyles. I live in Tampa, FL. I am a working wife and mother. My husband is an Alzheimer patient. We have three children. I am the primary caretaker of my husband. I have not yet reached the stage where institutional placement is necessary. As the disease progresses I know I will have to quit my job to care for my husband.

I would like to keep and care for my husband myself at home. Once I quit my job I will have no income except what he gets from Social Security and disability. As this disease progresses so will my medical bills.

My husband first began showing signs of Alzheimer's at the age of 45. My husband is 49 now. At the age of 45 we had two sons at home, one a senior in high school and the other a freshman in college.

The first signs were that he was not being able to remember the role of his supervision job. In January 1982, after some extensive testing, my husband was diagnosed. He was put on disability from his job in February.

We then applied for Social Security and were denied. Our sons were still dependents. We later applied again and were denied again. So we had to hire an attorney and again some extensive testing by different doctors, all at our expense.

In January 1983, 1 year and some great expense later, my husband was granted disability. At present I am able to work and keep my husband at home. What would happen if I became disabled and can no longer be the caregiver? With no work, no pension, how long could I keep him at home?

Although we have private insurance, what would happen when we cannot afford the expense not covered by our insurance? Our plans for the future are gone. All the years we have worked and hoped to enjoy retirement, gone. How long before my husband and I would have to depend on welfare to survive?

What would happen to our family? My support group has been my support. Answers do not come easily, especially in this day and age when the battle rages with regard to trimming the budget. I am encouraged by the fact that you took the initiative to come to the people and hear first hand the devastation caused by Alzheimer's disease.

Now that you have heard, I respectfully request that you act quickly, responsibly and purposefully to alleviate this growing financial devastation. I thank you sincerely for your interest and support in helping us to ease the burden.

Mr. **Waxman**. Thank you very much, Mrs. Pyles.

Mr. Patton.

STATEMENT OF MAX PATTON

Mr. **Patton**. My association with Alzheimer's disease came as the result of my mother acquiring the disease. Looking back now, the initial symptoms began in the 1970's and as symptoms progressed—she was diagnosed as having Alzheimer's disease and we had gone through a progressive deterioration whereby we tried hiring help with the house, taking care of her, going through retirement homes, with the aid of day care centers, nursing homes.

Finally she was brought to our home where we had done some extensive remodeling and she finished the last year or year and a half of her life at our house, passing away this last September.

If I have any expertise in this field it is probably in the relationship of young children with the Alzheimer's victim and perhaps I can answer some questions in this regard with you. Thank you.

Mr. WAXMAN. Thank you very much, Mr. Patton.

Mrs. Cury.

STATEMENT OF DELLA CURY

Mrs. CURY. My name is Della Cury and I live in Tampa, FL. I am 34 years old, married with one daughter. I am a graduate of the University of Louisville, KY, and I have been employed by a mortgage banking firm for the last 10 years.

In 1978, after 28 years of marriage, my father died from cancer and left my mother alone. She had been a mother of two and a homemaker all those years and she was devastated by his death. In 1979, my daughter was born. Mother came for 2 weeks to help. She had turned 54 that summer.

She could not cook nor help with the laundry. She was scared and cried a lot. She was changing and we did not know why. In 1980, my brother and myself helped my mother move to Tampa. We emptied the house into the garage and had a huge sale in preparation for the move.

During that sale, I learned that mother not only had trouble with her checkbook but she could no longer count change. At this point she was still covering up problems with excuses of being nervous or tired. Many of these observations could only be understood many months later.

In an effort to maintain her independence, my mother purchased a condominium in 1981 which was about 5 minutes from my house. That same year, I took her to a family doctor, psychiatrist, a clinical psychologist and finally to a neurologist. In 1982, my mother was diagnosed as having Alzheimer's disease.

Within the last 12 months we have searched for a place that would afford mother 24 hour care, comfort and companionship. The facilities that I have found would not take mother because she was younger than 62 years of age and also because of her existing disease.

In this area, now the most populous in Florida, nursing home costs average from $1,800 to $2,000 a month. We are presently paying over $1,700 a month for live-in care. Because of mother's age, this amount—which will accelerate when she moves to a nursing home facility—could rapidly eliminate her savings.

How can families of Alzheimer's patients handle these costs without assistance? This disease, which has become so feared and so prevalent, is not going to disappear.

We must do something now to help find a cure, to assist those families who are presently dealing with an emotional and financial crisis, and also to plan for the future. Much evidence indicates that Alzheimer's disease is hereditary. Should I become an Alzheimer's victim my husband and my daughter may become the main caregivers.

I hope at that time there will be more financial assistance and quality caregiving facilities available. I am aware of the current efforts to balance the budget and that Medicare and Medicaid are severely strained. There is great competition for each and every tax dollar. I would suggest some middle-of-the-road solutions be found.

As an example, most caregivers wish to keep their patient at home as long as possible. Perhaps a service delivery system could be established to assist caregivers. A service of this nature would allow the Alzheimer's patient to stay at home in a more familiar setting for a longer period of time and certainly would delay the devastating costs of a nursing home.

I would like to thank you—and certainly my mother would if she could—for the opportunity to tell her story to a committee that is so influential in the matters affecting our aging population. Thank you.

Mr. **Waxman**. Thank you.

Let me thank each of you for your testimony telling us about what must have been and continues to be for some of you a very difficult time for you and members of your family. Your stories are representative of what happens to millions of families who have been and will continue to be affected by this devastating disease.

The treatment, whether it is at home or in an institution, sounds like it is obviously very, very expensive. How have you managed to pay for these costs? Does Medicare help? Have any of you looked to Medicaid? Does your private insurance help you at all? Do members of the family help? How do you cope with the costs, the financial costs, of Alzheimer's? Yes, sir.

Mr. **Kelly**. If I may read from my prepared statement, I have had some experience. During the first few months that Julie was confined to a nursing center I was able to forecast what my assets would cover. I was shocked to learn that the $250,000 medical plan that was a part of my retirement package had an exclusion for mental disability.

Using a basic estimate of $25,000 a year, plus the 5-percent yearly escalation, it was easy to see financial devastation on the horizon. I attended Alzheimer's support group meetings sponsored by HRS. They are an excellent source of information and offered the opportunity to cry on one anothers shoulder.

It was during one of these meetings that I heard the greatest news and encouragement regarding financial matters. We were told by the speaker that those carrying the nursing home burden should investigate Medicaid and that only the patient's assets were considered in making a determination as to eligibility.

Heretofore, I had been advised that a spouse was completely responsible for the partner's care. In my particular case the major percentage of assets were in my name. This was not the result of any planning or deliberate action on my part. It occurred simply as a result of my wife's inability to make any decisions or to sign her name during the preceding 6 years.

I filed for Medicare. In support of a 12-page application, Health and Rehabilitative Services requested complete financial disclosure of all our assets going back a few years prior to date of application.

It was necessary to identify each individual asset, current status, and if disposed of how and when. This exercise required a considerable amount of effort and at times it could be difficult to show the continuity from one transaction to another.

I am not suggesting that this request for supporting data was unreasonable. The people at HRS were very cooperative and understanding of all the submissions I presented. Some of the clarifying data they requested was sometimes difficult to obtain from other sources.

Subsequently, Medicaid was approved for my wife. Unfortunately, or perhaps I should say fortunately, my prayers were answered and Julie died three weeks later.

Mr. WAXMAN. Mrs. Pyles, are you getting any help financially from Medicaid or any other care?

Mrs. PYLES. Right at present my husband is on Social Security disability so Medicare does cover some of his doctor's expense. But the other is covered by my insurance. But when my husband gets into a stage where he might need extensive care, my insurance does not cover that.

Mr. WAXMAN. And how about Medicare? Will Medicare cover him if he needs to be in a nursing home?

Mrs. PYLES. No, sir.

Mr. WAXMAN. I knew the answer to that but I wanted that to be on the record. I cannot tell you how many of my colleagues in the Congress, people who voted these laws, think Medicare is going to pay for everything—Medicare will take care of it.

Of course, Medicare, as wonderful as that program is, is very limited when you get into a long-term care situation. With a nursing home, particularly, or some type of long-term facility, Medicare's coverage is very, very lmited—one of the great inadequacies in the law today.

Mr. Patton, what kind of financial help have you been able to acquire?

Mr. PATTON. We were very fortunate in that my mother had substantial savings and she did pass away before her savings were exhausted. However, the difficulty with Alzheimer's is that you do not know the course of the disease. You cannot predict how long the person is going to live.

So whenever you take into consideration what you have to deal with and how it is going to be paid for, you do have to kind of set things aside and plan a little bit. But that was one of the reasons why we had, in the last year or year and a half of my mother's life, moved her to our house.

We found that this was less expensive. We could go ahead and hire some people to come in and help. Medicare did take care of some of the supplies, some sickroom needs and also some of the doctor bills that we ran into—a portion of it, very little though.

We were just plain fortunate that she did acquire the disease later in life. She was in her early seventies when she was diagnosed and she passed away when she was 76. Had she lived several years longer, why, yes, we would have had some difficulties.

Mr. WAXMAN. Mrs. Cury?

Mrs. CURY. My mother is very fortunate to have savings which are covering her financial needs at the time. Because she is only 59 now and, as Mr. Patton said, you do not know how long it is going to last, her savings could be depleted totally. I am receiving no financial aid now but I anticipate it could happen that I would need that.

Mr. **Waxman**. Other than from your physician, how did you get information about Alzhemer's disease and its treatment? Did you get help from any community-based support groups? Would it have been helpful to have a central place to go to or a special number to call to get information? Any of you want to comment on that?

Mr. Patton.

Mr. **Patton**. Yes. If anybody is faced with the situation of having someone that they are in question about or needing some help right now, what I would suggest would be that you go to the front of your telephone directory and find the number for your Division of Family Services.

From this you can get direct help, you can get referrals and, most important of all, you can get in touch with support groups. Support groups are the backbone of the situation right now. Your day care centers are of great value in initial stages of Alzheimer's disease, they really are.

They were a lifesaver to us on several occasions. You have your churches and various community groups that are becoming interested now in Alzheimer's. Thank God for this. And there are private profit organizations that you can contact also that were of great help to us also.

Mr. **Waxman**. Anyone else want to add to that?

Mr. Bilirakis.

Mr. **Bilirakis**. Thank you, Mr. Chairman. I, too, would like to express my appreciation and commendation to all of you for your courage. I know it is very difficult for you to have to come up here and tell us your sad stories. But without it we cannot learn and we cannot help to educate the public.

It is very important that the general public be educated as far as this dreaded disease is concerned. So I do commend you. Yes, I will try to talk a little louder. It is just that I have got a virus in my tongue and I just cannot talk too well right now, which is probably just as well for a politician.

Mrs. Pyles, this private insurance that you had told us about, you are saying that the provisions of the policy allow coverage as long as you have your husband at home?

Mrs. **Pyles**. Well, as long as he is under a doctor's care, but no long term in a nursing home, no sir.

Mr. **Bilirakis**. So, if you were to put him in an institution there would be no coverage? You are satisfied of that effect?

Mrs. **Pyles**. Yes, sir.

Mr. **Bilirakis**. The insurance man has explained that to you, is that correct?

Mrs. **Pyles**. Yes, sir.

Mr. **Bilirakis**. Well, Mrs. Pyles, also, your husband is certainly one of the youngest Alzheimer's victims that I have heard of. Although I will tell you and for the benefit of the audience, a few months ago I received a letter—a letter was shared with me from a mother, I think from the Tampa area—whose, I believe it was a 25-year-old, son had been diagnosed with Alzheimer's.

We are not trying to put the fear of God into anybody as far as this disease is concerned but it is part of our real world and the elderly do not have a monopoly. I think we have already heard of forties and fifties. The elderly certainly do not have a monopoly as far as this dreaded disease is concerned.

How is Mr. Pyles progressing, ma'am, and also how have your children responded to his illness?

Mrs. PYLES. Well, my children—we are a very close family. My children are responding real good as far as we know that we are going to take one day at a time. My children have their lives to live but they still include their father in it.

I understand that he is not really right now, you know, as far advanced as others, but you look ahead. You just, you know, we take one day at a time but you look ahead. Through my support group, which has been of good support to me, I see the stages he is going into. I have not reached those stages but I try to prepare myself now for those.

Mr. BILIRAKIS. Thank you, ma'am.

Mr. Patton, I understand you had your mother in a nursing home and then you chose to bring her home. Can you tell us why?

Mr. PATTON. For two purposes, really. As I said before, the length of a person's life with Alzheimer's disease is unpredictable and there is also a great feeling of guilt that goes along with the people who are caring for people who have Alzheimer's.

You try very hard and yet it does not seem to be enough. It is hard to accept the fact that what you see today is the best it is ever going to be and it is never going to be any better—it is always going to be a little bit worse tomorrow. And when you have a person with Alzheimer's they really are totally helpless. They are not able to fend for themselves at all.

They are very vulnerable. As a businessman, I know how difficult it is to hire someone who is absolutely and completely honest and capable. But I feel that the retirement home and the nursing home that we had contact with were probably the very best that we could possibly have had.

However, there is always the feeling that there could be something happening in the way of personal thefts and abuse through nothing but frustration or whatever. It is totally unknowing to the family because the person that is affected, the Alzheimer's victim, cannot remember. They totally are absolutely helpless.

For unscrupulous individuals there is just an endless source of income in the Tampa Bay area if they wish to prey on these people, people who have no immediate family members who are taking care of them. It is not difficult to spot someone with Alzheimer's disease after you have lived around them or taken care of them.

So I think that was a very important aspect in our decision to bring my mother home. That plus the financial end of things. Also, I had a son who was going away to the University of Florida and there was just a room that was available in the house. We were able to remodel it in such a way that it disrupted our lives as little as possible.

Basically, that is it. I mean, we just plain felt better about it. We thought there would be less of a feeling of guilt when her life was over. If things reached a point where we could not cope with the situations, we could always go back to a nursing home. But it worked out that that was not necessary. My mother passed away at our house.

Mr. **Bilirakis**. Thank you, Mr. Patton.

Very quickly, at least for a couple of you, I wonder if you could share with us your opinion in terms of the knowledge, if you will, of the physician or physicians that you contacted as far as your loved one was concerned?

Were you satisfied that they had adequate knowledge? The reason I ask that question, I guess it is fairly obvious, is—and we have heard this directly from the medical profession—that they are starting now to orient and educate physicians as far as this disease is concerned.

Even though it is something that has been with us a long time, we really have not learned much about it until just the recent years. But, of course, that also follows for the medical community. I wondered if you have any quick comments as far as that, any of you.

Mrs. Cury.

Mrs. **Cury**. At the beginning, my mother was treated for a good while for depression and I believe possibly because of her age it was not considered. It was not until we finally visited the psychiatrist and then the clinical psychologist that we were eventually directed to the neurologist. At that point, I felt very comfortable that he knew what she had and that the diagnosis was correct.

I think when you go to support groups you hear the same things that you are familiar with and you know about and you know that there is not too much question about what you are living through. You know it is Alzheimer's.

Mr. **Bilirakis**. Thank you. Any more comments toward that? Yes, sir.

Mr. **Kelly**. Back in 1970 when my wife first experienced trouble my family doctor sort of threw up his hands because he suspected something and he referred me to a neurologist. After the CAT scan and some elaborate blood work Alzheimer's was confirmed.

When I asked the neurologist what was it all about he referred me to an article that had been published a year prior in the New York Times. Because he himself admitted that he had so little experience with Alzheimer's, that New York Times article of 1970, 1971 was the source of great information.

Subsequently, when I came to Florida the first neurologist I contacted said he knew about it but time proved he was not an experienced man. I had to change doctors because I learned at the support group that some of the treatment or some of the drugs being administered were not adequate because I had a wife at home climbing the walls. I thought it was Alzheimer's and I found out later it was the drug that was aggravating the condition.

So I say you have to be selective or very carefully try to find the best neurologist you can. But once more, I would like to add emphasis to the support groups. They are an invaluable group.

Mr. **Bilirakis**. They are wonderful.

Mr. **Kelly**. They are wonderful. You will come out of them sometimes devastated because you hear some of the stories that is only a forecast of what you are going to go through, But, without the knowledge, when your day comes you are lost. So you take it day by day and attend as many support group meetings as you can. Thank you.

Mr. **Bilirakis**. Thank you, Mr. Kelly. Thank you, Mr. Chairman.

Mr. **Waxman**. Thank you Mr. Bilirakis. We appreciate very much your testimony and your being with us today. Thank you very much.

Our next witness is Dr. Eric Pfeiffer of the Suncoast Gerontology Center for Health and Long Term Care. Dr. Pfeiffer has long been involved in the care and treatment of Alzheimer's patients as well as the medical research that is being done on the disease. I would like to welcome you to our hearing and thank you very much for being with us.

Any prepared testimony you wish to submit to the subcommittee will be made part of the record in full. Now, what we would like to ask you to do, if you would, is to summarize your testimony. Please try to keep it within 5 minutes so that we will have a full opportunity to question you.

STATEMENT OF ERIC PFEIFFER, M.D., DIRECTOR, SUNCOAST GERONTOLOGY CENTER, UNIVERSITY OF SOUTH FLORIDA MEDICAL CENTER

Dr. **Pfeiffer**. Chairman Waxman, Congressman Bilirakis, it is indeed a pleasure to be here. I do commend both of you for your vigorous efforts on behalf of Alzheimer's disease victims and for research on Alzheimer's disease.

We have, several days ago, submitted a full copy of our testimony to be included in the record but I simply would like to summarize some of the main points and then be available to you to comment on any remarks that you have or to respond to your questions which I think will be the most useful role that I could play.

Alzheimer's disease, of course, is a devastating disorder. It runs its course anywhere from 2 to 20 years and therein lies a great deal of uncertainty and a great deal of financial implications for planning.

It is caused by premature and progressive death of brain cells. In other words, Alzheimer's disease attacks the brain, the overall organ of adaptation. It is anywhere from the fifth or the fourth leading cause of death and accounts for half of the people in nursing homes.

Only about 10 percent of the population will get Alzheimer's disease, but 100 percent of our population have to face the fear of Alzheimer's disease. So that anyone who makes progress in conquering this disease will, indeed, deserve not only the thanks and gratitude of that part of the population that is affected but that part of the population which must fear it.

At the Suncoast Gerontology Center at the University of South Florida Medical Center, we have made Alzheimer's disease our No. 1 priority. We are involved there in promoting education as well as the direct services of prompt recognition and treatment of Alzheimer's disease.

We counsel very strongly the avoidance of hospitalization where this is not absolutely necessary since the hospital is frequently a very hostile environment for a person affected by Alzheimer's disease. We minimize against the use of medications because, as you have heard, they can contribute to additional problems.

In our view, the best place for Alzheimer's disease patients is at home for approximately 90 percent of those victims for 90 percent of the time.

However, that indicates that some persons from the beginning cannot be cared for at home and the vast majority of patients will, towards the end of their illness, in the last 6 months to 1 year, require institutional care.

There are a number of services that are available not only to patients, which include diagnosis and ongoing medical care, but also to caregivers. Unless caregivers are provided these services, they cannot continue to care. These include family support groups, adult daycare and respite care.

We, at the center, are currently embarking on a major attack on Alzheimer's disease that looks at both research, at the underlying causes of the disease, and what to provide to patients and caregivers now. We have a number of recommendations that include publicly funded daycare services for Alzheimer's disease patients.

We recommend further that Medicare cover psychiatric and counseling service for both patients and family members in order to assist them in the process of caring for such patients.

We recommend limited coverage of respite care services, both in-home respite care services and short-term respite care services in nursing homes. It is quite possible that all of these might possibly be funded through a voucher system in which the individual may make the choice as to how to apply such services.

Further, we ask your support in the restoration of Federal funding for the support of the national system of long-term-care gerontology centers which has greatly advanced the understanding of Alzheimer's disease on a national basis. I would be glad to respond to your comments and questions.

[Testimony resumes on p. 301.]

[The prepared statement of Dr. Pfeiffer follows:]

Testimony

given by

Eric Pfeiffer, M.D., Director
Suncoast Gerontology Center
University of South Florida Medical Center

Chairman Waxman, Representative Bilirakis and distinguished members of this Subcommittee, my name is Eric Pfeiffer. I am a geriatric psychiatrist and Director of the Suncoast Gerontology Center, which is a part of the University of South Florida Medical Center in Tampa, Florida. It is certainly an honor and a privilege to have this opportunity to present my statement on Alzheimer's disease to this House Subcommittee on Health and Environment.

Representative Bilirakis, I am aware of your keen understanding of the plight of Alzheimer's disease patients and their families, and I praise your leadership role in the area of establishing family support groups through the National Institute of Mental Health and the Administration on Aging.

Chairman Waxman, my staff and I know very well and work very closely with the Long-Term Care Center at UCLA/USC in Los Angeles, California. Dr. John Beck, the Director of that Center is both a close colleague and personal friend of mine. Dr. Beck has done much to advance the field of geriatrics and long-term health care for the elderly.

The Suncoast Gerontology Center is located in a four county area that represents one of the highest concentration of the elderly in the United States. In Pasco and Pinellas county alone, Americans age 65 and over represent 40% of the population. The Suncoast Gerontology Center and the University of South

Florida are concerned about the state of long term health care for the elderly. As Director of the Suncoast Gerontology Center, which was originally established under Title IV-E of the Older Americans Act of 1980 and funded by the Administration on Aging, I have a particularly strong interest in the federal government's role in the long-term care system for the elderly. As a geriatric psychiatrist, I am intimately involved in the diagnosis and treatment of Alzheimer's disease patients and their families.

Representative Bilirakis, you have asked me to discuss my experience in treating the Alzheimer's patient and what the Center's research activities are in this area. Therefore, I will in my statement cover the following:

1) the nature of Alzheimer's disease,
2) the research activities of the Suncoast Gerontology Center, and
3) my recommendations for the federal government's most appropriate role in the research, treatment, and cure of Alzheimer's disease.

THE NATURE OF ALZHEIMER'S DISEASE

Alzheimer's disease is a devastating disorder in which brain cells die prematurely and progressively, causing progressive memory decline and general intellectual deterioration. Alzheimer's disease is the fifth leading cause of death in America and it constitutes a major health and long-term care

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problem in that it accounts for over 50% of all persons admitted to nursing homes. Some 6.5 to 7% of all persons over age 65 suffer from it, so that 2 to 2.5 million people in the United States have Alzheimer's disease. As America grows older this number will increase due to the fact that the prevalence of the disease increases with advancing age. Thus, at age 65 the incidence of the disease is about 1%, while at 75 it has increased to 10-15%, and at age 80-85 it has increased to 20 or even 25%, resulting in the average figure of 6.5-7% for all those persons age 65 and over. Alzheimer's disease is not simply a manifestation of old age. It is a disease, whose course can run from 2 to 20 years after symptoms are first recognized. The impact goes beyond that of the afflicted individual: it constitutes an enormous burden to individual families and to the entire health-care system. It is the number one destroyer of the quality of life in the later years.

Recognition and Diagnosis

Alzheimer's disease begins like rain in the night. It begins gradually and often it is months or even years before a correct diagnosis can be made. While Alzheimer's disease is a disease which primarily destroys memory, its initial manifestations are often more subtle, less frank, and they occur in the area of feelings and of changed behavior, rather than in overt memory loss. Depending on the personality of the individual affected by the disease, the symptoms may include depression, irritability, social withdrawal, decreased work performance, and occasionally isolated acts of inappropriate behavior. Sometimes a spouse notices difficulty in the marital relationship and may seek marital counseling. At other times work performance becomes so poor that the patient may be at risk of getting fired or retired prematurely. When any of these symptoms occur in persons in their 50s, 60s and 70s, it is important to be alert to the possibility of Alzheimer's disease.

The diagnosis of Alzheimer's disease can be made by any properly trained physician. This could be an internist, family practitioner, a neurologist, or a psychiatrist. Unfortunately the actual diagnosis is not often made during the early stages the disease but rather when memory deficit has become obvious and has already reached considerable severity. Diagnosis of Alzheimer's in an individual still living comes about through a process of elimination: the ruling out of any other forms of dementia that can be brought on by a stroke, excessive alcohol and drug use and many other things. A biomedical diagnosis of Alzheimer's can only occur through an autopsy. As a result, it is very common to see people diagnosed with Alzheimer's disease inappropriately by a well-meaning physician who has not been trained in diagnosis and assessment.

What is necessary to make the diagnosis of Alzheimer's disease? First, a history of gradual personality change, social withdrawal, lessened work performance and evidence of memory deficit. Second, there must be formal documentation of memory and intellectual deficit using anything as simple as the Pfeiffer Short Portable Mental Status Questionnaire, the Folstein Minimental Status Examination or a more complex battery of neuropsychological tests. Third, there must be a thorough physical and neurological examination, including appropriate lab tests to check for liver, kidney, vitamin or other metabolic abnormalities which could cause reversible memory loss. Finally, there may be value in specific neurophysiological test procedures such as the CAT scan, the NMR scan, the electroencephalogram and where available, the PET scan. Unfortunately, in the early stages of the disease most of these tests are likely to be normal. The most important method is still a very, very careful history taken from the person who most closely lives with and observes the affected person. Most often this is a spouse.

Impact of Alzheimer's Disease on the Patient: Primary Symptoms and Accessory Symptoms

Alzheimer's disease has an increasingly harsh impact on the affected patient. Initially only some mild personality changes occur. As the disease progresses, frank memory deficit occurs and the ability to make decisions decreases. As the disease progresses further, the person's capacity for managing his own affairs, his own household as well as caring for his own body, in terms of activities of daily living, also becomes impaired. Still later, the ability to speak, to find words and to respond to the communications of others first decreases, and finally disappears altogether. In the end, some of the automatic bodily functions, like swallowing and toileting functions, also disappear and the person becomes entirely dependent on someone else. All of these manifestations are the primary symptoms and the direct result of Alzheimer's disease. However, in addition many patients develop depression, anxiety, agitation, delusions and paranoid ideas in response to their illness. These secondary or accessory symptoms further complicate the disease, increasing the patient's own suffering as well as the burden to the caregivers.

Medical Care of the Alzheimer's Patient

Because we don't yet understand the cause, we can not cure Alzheimer's disease. We can only relieve the symptoms, educate the family and help them prepare for the inevitable. The provision of ongoing medical care includes a number of elements, among them:

- prompt recognition and treatment of other medical problems
- avoidance of hospitalization whenever possible, inasmuch as hospitals constitute a hostile environment for patients with Alzheimer's disease
- utilization of simplified diagnostic procedures, preferably at home or in an outpatient setting, when these are required

- minimization of medications, especially of cardiovascular and psychotropic medication
- maintenance of physical and social activities

While the basic cognitive and intellectual symptoms associated with Alzheimer's disease are not yet responsive to any specific form of treatment, a variety of associated emotional symptoms such as depression, paranoia and delusions, agitation, hostility, and belligerence are highly responsive to treatment. In regard to patients with delusions and those with hostility and belligerence the use of low doses of the major tranquilizers, including such drugs as Mellaril, Haldol, etc., often times in a single bedtime dosage, are highly productive. Somewhat more controversial and complex is the issue of using antidepressant drugs to treat severely depressed patients with dementia. In the early stages the use of the antidepressant drugs may very well be justified when biological symptoms prevail. On the other hand one must be very careful to monitor possible side effects from these drugs. The use of psychological interventions, including assisting the patient to cope with the occurrence of the illness, the provision of ongoing tender loving care, including extensive physical contact on the part of primary care givers and continued extensive social interaction opportunities, may be more helpful than antidepressant drugs. Also the use of physical exercise, and such activities as dancing or involvement in music activities may also be helpful.

The best place for patients with Alzheimer's disease is in their own home. It is my opinion that with appropriate support approximately 90% of patients with Alzheimer's disease can be cared for at home for some 80-90% of the duration of their illness. However, this is not the current situation. Alzheimer's patients are more often than not being institutionalized earlier than is necessary. If this continues the eventual cost, first to the family and subsequently to the state and federal government, largely through Medicaid payments for nursing home care, will constitute a "budget buster" at both the state and the federal level. As you know state legislatures and the federal government have already begun to experience the dramatic impact of the coming increases of these expenditures. Unless we make it more feasible for families to care for patients with Alzheimer's disease at home for longer periods of time, the results will be both humanly and fiscally irresponsible.

In this regard the families of Alzheimer's disease patients are a precious resource which we can ill afford to exhaust or to stress to such a degree that they themselves become patients.

Criteria for Institutionalization. For those that must be institutionalized we have established a number of criteria to assist families in determining when a patient should be admitted to an institutional care setting. These include:

- inability of the patient to participate in his own self care

- inability of the patient to cooperate in his own self care
- paid caregiver quits or becomes disabled
- the primary caregiver, for whatever reason, can no longer continue to provide care

There are many reasons for the difficulty in determining the appropriate time for institutionalization. The possible views of others in the family about such a move, like feelings on the part of the caregiver of guilt and failure in being unable to continue to care for the patient at home and fear that the patient may not receive good care in a nursing home all affect the decision-making process. Some of these fears can be overcome by counseling the family about the wisdom of making such a decision late in the disease and of carefully choosing an appropriate nursing home for the patient.

Alzheimer's Special Care Units. Some experimentation is currently beginning to develop in the area of specialized nursing home units for Alzheimer's disease patients. A number of nursing homes have established specialized units in which only Alzheimer's disease patients are cared for. These generally require less in physical care of the patient and much more intensive interpersonal interaction and some increased staff to patient ration over those provided for other nursing home patients. Again training of staff is vitally important. Such specialized units may cost slightly more than standard units to operate but I think are very worthwhile to be considered.

The Impact of Alzheimer's Disease on the Family Caregiver

Alzheimer's disease really produces two victims, the patient and the primary caregiver. Caregivers must make enormous adjustments to the occurrence of Alzheimer's disease. They must gradually assume increasing responsibility for their affected relative. I often refer to this situation as having to live with a "siege mentality" in which they must constantly be alert to further changes in the patient's behavior as the disease advances. Rabins and Mace have referred to this state of affairs as experiencing a "36-Hour Day." The lives of many family caregivers become severely restricted to providing care for their relative and nothing else. Many times an Alzheimer's patient will out-live their caregiver, due to the health problems brought on by stress and the increased burdens of the day to day activities.

Services Provided to Family Caregivers

In an effort to ease the burden of being an Alzheimer's patient caregiver and to ease the cost by providing alternatives to institutionalization, the medical and social services communities have devised a number of services that are available to the caregiver.

As a result of a conference that the Center conducted in Atlanta, Georgia last August, a manual on "Issues in Long-Term Care: Case Management, Elderly Abuse and Protective Services, Guardianship, and Respite Care" is now available from the Center.

The manual addresses issues that every caregiver should understand and provides helpful up-to-date information that is vital to being a healthy, successful caregiver.

Case-Management Services. Given the complexity of this disease and its impact on many areas of functioning in both patient and family caregiver, the need for case-management services is obvious. Case management is a service which assesses the functional status of both patient and caregiver, and on the basis of this assessment, designs and arranges for the most appropriate package of services suitable to that family in a specific community. Case management is an ongoing function which reassesses the family's status and redesigns the appropriate and needed services as conditions change. Several excellent manuals on case-management services are now available (see list of references).

Family Support Groups. Family support groups constitute a most important service for family caregivers. Family support groups accomplish a number of goals for family members:

- they provide understanding of the disease, including its diagnosis, ongoing medical management, long-term outcome and prognosis
- they can provide emotional support for individuals coping with the impact of the disease
- they can provide practical solutions and specific coping strategies for the various stages of the disease

- they can provide information about available community services to lighten the caregiver burden of the family member

A member of our staff at the Suncoast Gerontology Center, Lillian Middleton, M.S.W., has written a valuable manual entitled "Alzheimer's Family Support Groups: A Manual for Group Facilitators." This manual provides assistance for the development, organization, and maintenance of support groups for family members of Alzheimer's disease patients and is available from the Suncoast Gerontology Center.

Respite Care. Caregivers participating in family support groups have identified the various forms of respite care as their most important unmet need in permitting them to continue to care for their affected relative at home. Respite care can be provided in a variety of settings. For the most part it provides respite from the caregiver duties to the family member. Some forms of respite care also offer specific services directly to patients.

The three most common forms of respite care being developed but not yet available in every community, include:

(a) adult day care, including day-care programs specializing in the care of Alzheimer's disease patients;

(b) in-home respite-care services, utilizing either trained or untrained respite-care workers to provide episodic or regular periods of relief to the family caregiver; and

(c) short-term institutional respite care programs in which patients are admitted to a specialized nursing home, hospital, or congregate living facility, while the primary caregiver is able to go on vacation, attend to business or to medical care problems.

Grief Support Groups. Care of the family caregiver does not terminate with the death of the patient. It is important to provide some opportunity for grief support and for grief resolution for these patients who have been in an intense caregiver situation for many years. Often the process of grief resolution is complex because of feelings of guilt and anger on the part of the family caregiver and because the almost all encompassing role of caregiver gives way to a relatively "roleless" existence. As part of such grief support, group explorations are then begun on how to best resume life and what alternatives the family member has for "life after Alzheimer's disease." Some family members wish to continue to work with the issue of Alzheimer's disease.

The Impact of Alzheimer's Disease on the Health-Care System

The impact of Alzheimer's disease on the health-care system is also a massive one. Alzheimer's disease and related dementing disorders account for approximately 50% of persons admitted to nursing homes. The cost to government, both state and federal, has increased massively for nursing home care; a large proportion is for care of the Alzheimer's disease patient. Up until this time, care for the patient is paid almost entirely by Medicaid, through both federal and state sources. Medicare does not make any significant contribution to the long-term care of Alzheimer's disease patients. I will address this again in my recommendations.

A Perspective on Research Efforts in Alzheimer's Disease

Despite the fact that the press and the electronic media report "breakthroughs" in Alzheimer's disease research with some frequency, giving the impression that the problem is almost totally solved, the actual facts are otherwise. What is happening is that significant advances in our research understanding of Alzheimer's disease are misinterpreted as breakthroughs in either the clinical cause or clinical cure of Alzheimer's disease. Unfortunately this often produces high hopes and deep disappointment for many patients and families. For this reason I would like to offer a somewhat more balanced view of what progress is being made in Alzheimer's disease research.

It is my interpretation of the various biomedical research efforts that substantial and encouraging advances have been made in understanding the pathological processes involved in Alzheimer's disease, but this understanding is far from complete. In terms of arresting the further death of brain cells, only minimal progress has been made so far. I would estimate that full understanding of the Alzheimer's disease process is some 5-10 years off, while successful efforts to arrest the disease may be some 5-15 or even 20 years off. Research in this area is extremely complex, expensive and challenging. Support is needed for long-term research efforts from both governmental and private resources.

The five most promising research ideas currently being pursued include:

(a) the acetyl choline theory which assumes that the neurotransmitter substance (acetyl choline) is deficient and is either causally or concomitantly related to the disease;

(b) the viral theory which assumes a virus, virus-like, or sub-viral particle infects brain cells and causes eventual death of these cells, thus causing the disease;

(c) the immune deficiency theory which assumes that deficiencies in the aging immune system contribute to the body attacking its own cells, specifically brain cells required for memory and intellectual functioning;

(d) the heredity theory which assumes that complex heredity mechanisms (genes) are responsible for at least some cases of disease; and

(e) the toxic effect theory which assumes that as yet unidentified toxic substances from the environment reach the involved brain cells and cause their death.

Each of these theories has a significant body of research findings to support it, and of course combinations of these several theories are also distinctly possible.

The Suncoast Gerontology Center's "Attack on Alzheimer's Disease

Alzheimer's disease is the Suncoast Gerontology Center's #1 priority. We are committed to finding a cure and improving our understanding of how to care for patients and families alike. Currently the Center is conducting research in the following areas:

1) the improved diagnosis of Alzheimer's disease,
2) the effect of experimental drugs on symptoms of Alzheimer's disease,
3) the effect of day-care and in-home respite care services,
4) the underlying biomedical causes of Alzheimer's disease,
5) the collection of epidemiological data on Alzheimer's patients to establish an Alzheimer's Disease Registry, and
6) the utilization of neuropsychological computer tests in early diagnosis of the mild to moderate stages of Alzheimer's disease.

We have just completed the establishment of a $1 million Endowed Chair on Alzheimer's Disease which we hope to have filled by the end of 1986. It is the second of its kind, the first being located at the University of California at San Diego.

The Suncoast Gerontology Center also provides a range of services for both the patient, the family and the health-care professionals that serve them. For the patient, we conduct a Memory Disorder Clinic to diagnose Alzheimer's disease and to provide treatment of symptoms which are associated with the disease, such as depression, agitation, hostility, and delusion.

For the family, the Center provides the following services:

1) support and practical planning
2) family support groups
3) advise on available community resources including day-care, respite care, and guardianship
4) assistance in maintaining patients at home for as long as is beneficial to both the patient and the family
5) assistance to families in making decisions about institutional care, and
6) grief counseling and grief resolution programs.

For health-care professionals and other service providers the Center provides training in the diagnosis and management of the disease to practicing primary-care physicians, information on available community resources and research developments concerning the disease, and training to respite-care and day-care workers.

RECOMMENDATIONS

My recommendations for the federal government's role in long-term health care, particularly in the diagnosis, treatment and cure of Alzheimer's disease changes in the financial coverage of services under Medicare that will maximize the ability of family members to continue to care for their afflicted relatives in the homes, and a biomedical research program that will ultimately allow us to understand and stop the disease.

Recommendation #1

The Establishment and Funding of Day-Care Programs

Family members of Alzheimer's disease patients have indicated to us both locally and nationally that the availability of specialized day care programs for Alzheimer's disease patients in local communities constitute one of the highest priorities. This would give family caregivers a much needed respite and would provide a stimulating and varied environment for patients affected by the disease. At the present time no public funding for such facilities exists and only a very few programs of this nature are available, even though they are much needed. There obviously is a reciprocal relationship between the availability of funding for such programs and the establishment of such programs and it is our recommendation that such programs be both established and funded through public programs for the benefit of patients and families afflicted by Alzheimer's disease.

Recommendation #2

Medicare Coverage of Psychiatric Services to Treat Secondary Symptoms

We recommend that the physical barriers to the utilization of psychiatric services to treat the secondary or associated symptoms of Alzheimer's disease (depression, agitation, delusions) be removed, so that family members will have ready access to appropriate treatment of these behavioral manifestations. If this is provided, many more patients with Alzheimer's disease can remain in their homes for longer periods of time.

Recommendation #3

Medicare Coverage of Limited Respite-Care Services and Nursing Home Care for Patients in the Late Stages of the Disease

We recommend that federal legislation be amended to make available a new covered benefit under Medicare to provide a limited number of respite-care days in nursing homes as well as a limited period of time for intermediate care in nursing homes for patients in the late stages of Alzheimer's disease. Such benefits, to be awarded only when adequate assessment and diagnosis has been made which confirm the patient's suffering from Alzheimer's disease and having entered the late or near final stages of the disease.

Recommendation #4

Restore Full Funding to the Long-Term Care Gerontology Centers

The alternate solutions to Alzheimer's disease lie in research. We have, over the past five years, built a network of research and development centers that were established to initiate cost efficient systemic changes that would address the unique and growing needs of the elderly. The withdrawal of support, by the Administration on Aging, came at a time when investment was just beginning to bear fruit. The discontinuation came in spite of Congressional action to include specific report language in the Health and Human Services Appropriations bill, that specifically mandates maintaining ...the presently funded long-term care gerontology centers." (House of Representatives) and directs the AoA ...to continue to fund the eleven presently funded long-term care gerontology centers." (Senate)

On January 3, 1986 I sent a letter to Ms. Carol Fraser Fisk, Acting Commissioner of AoA, inquiring as to the time frame and manner for the implementation of the provisions of the 1986 Labor -HHS- Education Appropriations Act (H.R. 3424). I have not received a response from Commissioner Fisk as of today.

By the year 2,000 there will be 40 million people over age 65 in America. The need for improved long-term health care and research solutions that will address the health problems of old age will continue to grow. We appreciate that in an arena of budget constraints very careful and prudent calculations of the potential cost of any or all of these programs must be made prior to any attempt to implementation. However, we similarly believe that the research and development being conducted by the Long-Term Care Gerontology Centers will result in the eventual reduction of long-term care public costs.

We are grateful to you, Chairman Waxman and Congressman Bilirakis, for your vigorous support of our efforts at the Long Term Care Gerontology Centers to improve the lives of older persons in Florida, California and the nation. I am especially grateful for your dedicated effort on behalf of patients and families affected by Alzheimer's disease. We again wish to thank you very much for the opportunity to participate in this important hearing.

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Mr. Waxman. Thank you very much. Thank you for those very specific recommendations.

You know, we usually think of treating disease based on a medical model or what is called acute care. You have a medical problem, you go to a doctor. You go to a hospital if necessary, take your medicine, and recover.

But, Alzheimer's does not fit into that category and our Medicare system is based on that model, based on paying for those services where acute care is needed to recover. So, we do not have Medicare paying for what are called social services like adult daycare. And, of course, we know Medicare does not even pay for the prescription drugs and we have limited, extremely limited, mental health benefits.

Now, Alzheimer's patients need medical services but they also need these other types of services.

I would like to hear from you what type of services, if we are looking at expanding Medicare, that we ought to have Medicare pay for, and maybe a voucher system or some other way, that would be related to some of the care needed by Alzheimer's patients

Dr. Pfeiffer. Well, I would like to respond to that because you are certainly right that this is a long-term care problem which probably epitomizes long-term care issues in general in this country.

It is probably the largest of the long-term care problems. Medicare does cover some of the costs of direct care of Alzheimer's disease patients in hospitals and a minimum amount in outpatient settings.

What is totally not covered are any services which essentially allow family members who currently provide fully 80 percent or 90 percent of the service to Alzheimer's disease to continue to do their job, because we see the other side of that.

If families are not supported in this, they will, much earlier on, be unable to continue to care and have the person go into a nursing home, downspend their dollars, which, in the average American middle-class income, may be somewhere between $10,000 and $20,000 that somebody has in their accounts, downspend it and then become a public responsibility when they go onto Medicaid coverage.

We wish to support a system of services to families that will allow them to care for Alzheimer's disease longer for two reasons: One is because it is the best place for the patient, and second, because it is probably the least expensive place to provide long-term care.

These services that we have found useful have included faculty, family support groups. We have been very active in stimulating the growth of family support groups. In this area, there are now about 30 support groups, about 25 of which we have taught how to do it.

When we talk to the people in family support groups, the next thing they need is daycare and respite care. And I think this is coming out of their own pocket. In addition, I think there are not enough services available as yet.

The State of Florida has taken a stand and recently created a small amount of money for State-funded daycare services. The

State has further developed a number of Alzheimer's disease memory disorder clinics at its three medical schools, and one associated medical center, and some respite care services.

But this is a miniscule step in the total magnitude of the number of patients with Alzheimer's disease in this State and in the Nation as a whole.

As we examine various options of support, these options for daycare services and for in-home respite care services, and for information dissemination in which we are very active and very strongly support, are at a minimal cost compared to years and years of inpatient nursing home care at the public expense.

I think it will need some small additional commitment in order to avoid longer costs down the road coming out of both the State and the Federal public purse.

Mr. **WAXMAN**. So, if we as policymakers are going to decide how to approach this problem and where to put the money, if we think only about paying for that nursing home care and nothing else, we are going to be putting more people in the nursing homes probably earlier than otherwise would be the case. What you are suggesting is, we put money into services that will allow patients to stay at home. We need to have daycare centers and respite care and help the families through support groups to learn how to cope with this whole thing and not push people into nursing homes.

Dr. **PFEIFFER**. Yes. Well, you have heard some of the heroic statements of some of the caregivers. In my human experience I have never found such heroics as those families you have taking care of Alzheimer's disease patients. It is really a tribute to human strength and courage to see that.

But, they can only do this so far and I think rather than wait until their last dollar has been spent and then throw them on the public purse, I think to support them while they still have their own resources will make those resources go further and oftentimes will not require, as you have heard in some of the examples cited, any lengthy nursing home care at the public expense.

Mr. **WAXMAN**. Let me ask you this, as a medical expert who deals with Alzheimer's. Very often we hear about Alzheimer's as if there is virtually nothing that can be done to help these patients. Many people believe the best we can do is simply put these patients in some kind of setting and let the disease take its course.

But, I would like to know, are there things that can be done? Can depression be treated? Is treatment available to overcome some of the conditions associated with the disease? Is there something that can be done medically, first of all, that can improve the quality of life for Alzheimer's patients? Second, where something medically can be done, does Medicare pay for it?

Dr. **PFEIFFER**. A very cogent question. Yes, there are a number of things that we can do. First of all, as I said, an accurate diagnosis, and second, a humane way and a hopeful way of communicating that diagnosis, and third, trying to set up a system of support.

In addition, while current knowledge in medicine does not permit us to reverse the brain cell death—this will come only through research—a number of patients with this disease simply experience memory loss without significant changes in their personality structure.

Others do experience very disturbing additional symptoms—delusions, hostility, aggression—much of it stemming from the frustration of not being able to do what one used to be able to do. It is not that they become hostile. They become frustrated in the process, hit out at other people.

Oftentimes, counseling and medication can diminish this so it becomes a momentary incident, also blissfully to be forgotten by the patient, rather than a change in personality toward a hostile status. Similarly, depression in response to the fact that one can no longer do what one used to be able to do.

Can we treat it both psychologically and through medication? This requires very close supervision of medication, however, because Alzheimer's disease patients are very sensitive to some of the side effects.

Does Medicare pay for it? It currently pays 40 cents on the dollar for such services with a total limitation of $250 per year on an outpatient basis. This is inadequate. I think this benefit should be made on an equal basis with general health care aspects, not treating this as a mental disorder only, almost as if though this was the patient's own responsibility.

I think this is shortsighted and in the long run too expensive. I would recommend that we place the psychological counseling service on a par under Medicare coverage with general health care services.

Mr. **Waxman**. So, in other words, if you go for medical care for Alzheimer's there is a limit on it because it is—under the law—categorized as a psychiatric problem? But if you went to a doctor and wanted medical help for a kidney stone you would get reimbursed for the care there in a different way?

Dr. **Pfeiffer**. That is correct. I think the system is prejudicially arranged as it relates to mental disorder. Alzheimer's disease is under this for reimbursement purposes, not for our understanding. Alzheimer's disease is——

Mr. **Waxman**. Medically, it is not any different, is it? It is a deterioration of bodily functions; it is a physical problem or disability.

Dr. **Pfeiffer**. It stems from this, Chairman Waxman, that Alzheimer's disease is a physical disease affecting nerve cells but one of its manifestations is changes in behavior. This fact, at times, gets interpreted that this is a mental disorder.

It clearly produces changes in behavior such as changes in memory and depression and hostility. But it is caused by death of brain cells that are in no wise the responsibility of the individual who has the disease or his family.

Mr. **Waxman**. Thank you very much.

Mr. Bilirakis.

Mr. **Bilirakis**. Thank you Mr. Chairman. Dr. Pfeiffer, it is good to see you again. Thank you so much on behalf of all of us for the great work you do on this subject.

Sir, with the increase in the rate of elderly in this country, we will have a continued growth in the number of Alzheimer's victims. I think we can safely assume that. And with that will come the need for trained health professionals to care for these people.

So I ask you, do we now have a shortage, in your opinion, of health professionals who can accurately diagnose and treat Alzheimer's? And, if we do, what in your opinion, could be done to correct the situation so that we can better meet the needs of the future?

Dr. **Pfeiffer**. Several years ago relatively few physicians were very knowledgeable about this disease. This has begun to change and now I think in every community there is a handful of individuals who make this an area of special competence and expertise, while it is not yet a generally well known illness.

What we can do about it is to invest in training of health care professionals and associated health professionals such as nurses, doctors, social workers, at our schools of medicine, to assure that this gets taught, not only for the next generation of health care professionals, but for those generations who, like myself, never had any training in geriatrics when we went through our schools.

I think it needs to be included in continuing medical education programs and I think the medical schools and health centers in general have a responsibility in this, but I think they need stimulus both in terms of reward systems as well as mandates that this be done.

Mr. **Bilirakis**. What sort of stimilus or reward systems?

Dr. **Pfeiffer**. Well, I think the national network of long term care and gerontology standards has probably been the most remarkable of the efforts that the Administration on Aging has supported in widening the understanding about this disease.

It has on a regional basis created a network of one regional center per region and that regional center then has been mandated to provide education and training in the surrounding States in the region.

We have had that mandate and have carried this out until recently when AOA funding for this was discontinued*

Mr **Bilirakis**. Should we, in some way, tie in some of the Federal funding—the Medicare funding, for instance, that goes into residencies, things of that nature—somehow tie some of that in to basically encourage and motivate more study in this area?

Dr. **Pfeiffer**. The mechanism for doing so, I believe, should be added on, not substituted, in order to show that we are serious about this. My own view is that for every dollar invested in training I think the payoff is going to be greater than almost anything else we can do, actually, in terms of service delivery. I think the multiplier effect of training is extraordinarily high and I think the stimulus at the Federal level would be very important in this.

Mr. **Bilirakis**. Thank you. Doctor, it is my understanding you have done some work in assessing the status and functioning of Alzheimer's patients. If we were to develop a Federal policy, as we have been discussing here, that would target payments or programs to Alzheimer's patients—your voucher system concept, if you will, or whatever—is there a way to determine who would be eligible and how to assess the progress of the disease and the need of services?

Dr. **Pfeiffer**. Yes, sir; there are. But it is not a simple mechanical solution. There are a number of psychological tests, some of them very brief, some of them very reliable. But there are also individual personal factors that really require a case-management strategy to assess what is needed at a particular given point in time.

This includes not only assessment of the patient but, importantly, assessment of the caregivers that are available and the ability of them to take on the burden, whether they have a job or not, whether they have the psychological makeup, whether they can be taught to take on this responsibility.

There are assessment mechanisms but I would counsel against any mechanical application of an assessment procedure without the intervention of a clinician to integrate these findings from assessment procedures.

Mr. **Bilirakis**. Well, anything that takes place toward that end hopefully would include your input, Dr. Pfeiffer. I might add, Mr. Chairman, that certainly we, Members of Congress, are also learning about this disease. I know Dr. Pfeiffer furnished my office with a film a few months ago on Alzheimer's and we sent out notices to the Members of Congress to congregate at one particular location and take a look at the film. There were a few Members or staff that attended.

Actually these hearings and the things we are doing up there in our hearings are basically not only educating us and educating the general public, but also a need as far as Members of Congress are concerned. That is the only way we are really going to be able to tackle this.

I appreciate, again, your coming, sir. Thank you Mr. Chairman.

Mr. **Waxman**. Thank you, Dr. Pfeiffer.

Our next panel will focus on the issue of financing of services for Alzheimer's disease victims and their families.

Ms. Larelle Szumski is director of Social Services at the Bay Tree Nursing Center which serves many Medicaid patients with Alzheimer's disease. Mr. W.B. Mackall is Special Assistant to the Director of the Veterans' Administration Medical Center in Bay Pines. That center treats veterans with many dementing conditions including Alzheimer's disease. And representing the Health Insurance Association of Amerca is Mr. Henry Arnold who is vice president for Sales of the Gulf Group Services Corp. in Jacksonville. Mr. Arnold will discuss what the private health insurance industry is doing to cover services for Alzheimer's patients. I would like to ask this group to come forward, please.

We want to thank the three of you for joining us here today. The testimony you have submitted to the subcommittee will be included in full in the formal record of today's hearings. I would like to ask you to please take 3 or 4 minutes to summarize your comments and then we will have some questions for you. We would like to hear from each of you before we begin with questions.

Ms. Szumski.

STATEMENTS OF LARELLE A. SZUMSKI, SOCIAL SERVICES DIRECTOR, BAY TREE NURSING CENTER; WILTON B. MACKALL, SPECIAL ASSISTANT TO THE DIRECTOR, VETERANS' ADMINISTRATION MEDICAL CENTER; AND HENRY A. ARNOLD, ON BEHALF OF HEALTH INSURANCE ASSOCIATION OF AMERICA

Ms. **Szumski**. Thank you. Representative Waxman, I am very honored to be here. I told, in my lengthier testimony, some of the stories of the victims of Alzheimer's and other kinds of long-term illnesses with which I deal daily.

My testimony, however, could never equal the honesty, the courage, and the poignancy of the stories you have heard already today. Long-term care is a difficult problem and something we must all look at very carefully. It is in all of our futures. It is everyone's responsibility to be a part of the cost of long-term care.

We have a larger aging population. We have a population that will grow and need help. I am going to be one of those aging baby-boomers. I am going to need help. How many young employed taxpayers will we have to support that? We must rethink our attitudes toward who is going to pay for us. I think it is a moral responsibility. I have witnessed decreasing financial support for government programs in the years I have been in this field.

Sometimes people feel they are being sold down the river. They come in my office and they lay their Medicare card out, then lay down all the other insurance cards they have and I have to tell them I cannot help them, they cannot use that.

I have to tell them, people who are proud, that they will spend their money and they will apply for Medicaid. They will be on welfare. I have to tell wives, you will have to survive on as little as $84.42 a week so that your husband can receive care.

I will search, I will call, I will beg, I will borrow, to find answers to help the problems. But I do not have all the answers. I need help and I am very glad you asked me. I love my work very much, but I cannot fix it. We need custodial care insurance. We pay for everything else. We pay to prevent fire and floods, in case we get injured in auto accidents. We need to pay in case we need long-term care.

If there is only 10 percent, as Dr. Pfeiffer just told us, I think the other 90 percent of us would be able to support a program like that. We are at a crossroad. Alzheimer's disease is not the only chronic long-term devastating illness. I have spoken of many of them in my testimony.

There are a lot of ways to try and solve the problem. I do not have all the answers but I know we need help. I think we must realize we cannot save for inheritances any longer. But we must save to care for ourselves. We must develop creative, cost-effective ways to provide long term care in the home and perhaps intermediate facilities, and in long term facilities.

I care very much about every one of you and I hope that this hearing will solve problems. I am really glad that you asked me.

[Testimony on p. 326.]

[Ms. Szumski's prepared statement follows:]

STATEMENT OF LaRELLE A. SZUMSKI

The time for action is overdue. Thanks to the publicity attached to the financial devastation associated with the long term care needs for victims of Alzheimer's Disease, the plight of our nation's elderly who need long term care and who lack the resources for that care has come to our attention. The assistance programs in existence today are effective, but they do not encompass many of the cases with which I must deal on a daily basis. I am a Social Service Director in a long term care facility and I witness the ignorance, embarassment, confusion, disillusionment, and devastation which faces the victims and their families. The action I am calling for need not come solely from you, our elected representatives, nor must it come from yet another government program for which we have dwindling sources of revenue. There is a moral issue involved in seeing that each citizen receive adequate health care throughout life and it is everyone's responsibility.

In order to understand the problems, we must first examine the programs as they now exist. They are as follows:

MEDICARE

Medicare is the federal health insurance program offered to individuals who are over 65 or disabled Americans. In the long term care setting, it provides up to 100 days coverage with the following criteria: You must

1. Have a minimum 3 day hospital stay.
2. Require skilled nursing care in a long term care setting within 30 days of discharge from the hospital.

Part A benefits provide 20 days of full coverage for room, board, and nursing care. On the 21st day, the patient is currently responsible to pay $61.50 per day toward his care. This amount can be paid by a supplemental insurance, if the person has it.

Part B pays 80% across the 100 days for therapy, medication, physicians, labwork, and equipment.

This will be helpful as long as the patient remains at a skilled level. Most victims of chronic illness like Alzheimer's Disease or Parkinson's Disease never use their Medicare benefits in a long term care setting. On admission, they are normally not at a skilled level of care. Even if they suffer a hip fracture or stroke, coverage cannot be substantiated for long. They are unable to follow the instructions of a physical therapist and cannot be rehabilitated. H.M.O.'s are covered under the same criteria and offer even less benefits, at times.

I could go into another testimony entirely regarding H.M.O.'s and the changes in Medicare coverage for even short term care, but that will be saved for another hearing. Medicare coverage in the long term care facility has markedly decreased. More and more elderly are having to pay for the cost of even a two month rehabilitative stay at $4000 - $5000 per stay.

Medicare pays for one hundred days. What about the hundreds of days that these patients will require care?

PRIVATE INSURANCES

The bulk of medical insurance policies today are designed to supplement Medicare or to provide for skilled care patients. If a patient is admitted for custodial care, the most help he can expect will be for his medications and physician. Sometimes medications are not covered. Even one of the most comprehensive employee insurance programs - General Motors UAW Blue Cross - will only pay for care in a long term care facility after Medicare exhausts and if the patient continues to require skilled care.

However, insurances can place other restrictions on patients. A skilled terminal care patient who had paid premiums on an extended care policy could not get benefits because our facility was not J.C.A.H. (Joint Commission for Accreditation of Hospitals) approved. We are a skilled nursing facility with a superior rating from the Florida Department of Licensure. We are Medicare approved, VA approved, and Medicaid approved for skilled and intermediate care. We have an excellent reputation for rehabilitation. Yet, because we chose not to pay $1500 - $2000 for an inspection by J.C.A.H., this patient received no coverage from her insurance. She chose to stay with us because her daughter lived five minutes away, and she did not want to make another change at the end of her life. Luckily, she died and only had to pay for three months care after her Medicare exhausted.

I receive frequent calls from older people asking about an insurance policy someone is trying to sell them. They want to know if it will pay for long term care. 99% of the policies with which I am familiar, do not cover custodial care. The smart ones are the ones who call. Many older Americans are being cheated by promises of "nursing home coverage" or "we pick up what Medicare doesn't". Most of the people I have had contact with are willing to pay for insurance for custodial care. Very few policies are available. Due to the recent request from our government for custodial care policies, some companies are beginning to offer them. This will help the future. What about those who need help now?

MEDICAID

Medicaid is a state regulated financial assistance program for long term care. Federal guidelines are set for the program, but each state is allowed to run the program as it sees fit. Florida, due to its high concentration of elderly, has income limits lower than the Federal guidelines. The financial qualification for long term care are that an individual have assets less the $1700, and a monthly income less the $870. (Federal guidelines for income are currently $1008.00).

This program works well for those who fit the criteria but there are many cases who do not. If a patient has a monthly income of $1100.00, he cannot qualify for assistance. Yet the cost of long term care can run from $1500.00 to $2000.00 a month or more, depending on the cost of medications, room, board, ancillary services, and physician fees. The person becomes lost in the injustice of the system. If the patient is lucky, I will find a placement for him with a long term care facility that will accept him for his monthly income. Although my facility accepts Medicaid patients, they will not keep these people because doing so would increase the amount charged for private pay. Usually, I do not admit them and attempt to direct them to a facility who will keep them, so they do not have to suffer yet another change.

If the patient qualifies for assistance, he or she must pay all of his monthly income, less $30.00 for personal expense, each month for care. Then Medicaid covers the rest. However, there are many costs for patients which are not covered by Medicaid such as haircuts, over the counter medicines which are ordered by the physician, clothing, personal toiletries, etc., and must come from their personal resources. Families help out or the nursing home gives the patient donated clothing. Somehow we manage.

If the patient is married, there is another side of the coin. The well spouse may keep the home they share, a car, and whatever money he or she can protect before application for Medicaid. Then, he or she must live on one income instead of two. They must continue to pay for electricity, mortgage payments, repairs and upkeep on the home, their own health care needs, food, clothing and other bills. In the case of a wife who never worked outside the home, currently her income can be raised to $366.00 per month through a contribution from her husband's income. When she meets that income, she is not below the poverty line, so she qualifies for no assistance programs. She must survive on $84.46 per week.

Let us examine a typical example of the custodial care patient in a long term care facility. Mr. J. is in his mid 70's. He has been living at home with his wife who is also in her 70's. He has Alzheimer's Disease and, for the past five years, has had dwindling mental and physical function. His wife is no longer able to care for him at home and the cost of 24 hour home care is prohibitive. On admission, Mr. J. is ambulatory but he will wander away if not monitored. He has a short attention span, so he must be fed because he forgets to eat. He has poor muscle control and is incontinent of bowel and bladder. He becomes easily impacted because he forgets to drink enough water and his body does not digest food well. He appears to be confused, but some of the confusion stems from the fact that he cannot remember the word for what he wants. He becomes frustrated and combative at times, so he must be approached gently and carefully by staff. Sometimes safety restraints must be used to prevent injury to him and others. He frequently feels lost, and the anxiety he experiences must be controlled carefully by medication. He cannot dress himself, clean his teeth, comb his hair, tie his shoes, and all of his needs must be anticipated. Mr. J. was a salesman in a company and has Medicare, insurance from his employer, and a supplement for which he has paid high premiums for ten years. He has a monthly income of $1150.00 not including his wife's social security check. They have saved $40,000.00 from which they receive an interest check to augment their income. They jointly own a home. Mr. J. is not eligible to receive benefits from Medicare or his private insurance because he is considered a custodial care patient. If Mrs. J. used all the assets they have, Mr. J. would never qualify for Medicaid assistance. Even if he became a skilled care patient in a year, because a tube was inserted to feed him, his insurances would not cover him because it is not necessary to be hospitalized for this procedure and it would be initiated after the 30 day limit used by Medicare and most insurances.

Each day, his wife will visit. She will leave in tears and pray for his death - not only due to his illness, but because the spectre of poverty hovers above her with no help in sight.

Miss E. was a teacher during her lifetime and never married. She worked hard and invested her money so that she would be comfortable in her old age. She developed Parkinson's Disease and had been living at a A.C.L.F. (Adult Congregate Living Facility) until she could no longer live independently and required nursing home placement. She has a monthly income of $970.00 and her assets are dwindling. She faces a dilemma. She cannot qualify for Medicaid due to her income level, her insurances will not pay for her care, she has no home or family except an equally elderly brother who is trying to help her. She requires 24 hour care and could live another 5-10 years. I will have to find another long term care facility for her that will accept her for her income. I have worked with the brother for over a year and have offered him several solutions, but he has not acted. He never thought she would live this long. Perhaps he will decide to augment her income. If not, disaster is sure to come. If I am very lucky, I will find a placement for her. If not, what will I do? It seems unfair that one who devoted her life to educating America's children, cannot get assistance from the country she helped to build.

Mr. M. has been fighting the deterioration of his wife from Alzheimer's Disease for 30 years. Onset of symptoms, which were violent rages, began when Mrs. M. was 45 years old. He has taken her to the Mayo Clinic and to many experimental programs in his effort to help her. He has used much of his personal funds to do so. About 10 years ago, a trust was established by an attorney. Mr. M. is the executor of the trust which allows him to give his wife whatever income he wishes. He expressed concern about using all of their assets for her care and he would be left without anything to provide care for him in the future. Because of the nature of the trust, I suggested that he apply for Medicaid and say he would give her the income limit allowed by the program. When he applied, he wanted to be fair and offered to pay half the cost, which is more than the income limit. He was, of course, refused. He looks bewildered and will not reapply. He cannot understand why there is no help for someone who is willing to share some of the burden. He only wanted to save some monies for himself. If, at a later time, Mr. M. needs long term care, his monthly income will exceed the current Medicaid level, but will not be enough to pay the cost of long term care. What will he do when his assets are gone?

Mrs. P. came to our facility with a diagnosis of Leukemia. She is a widow who has adequate funds to pay for her care for some time and will qualify for Medicaid should she need it. She has Medicare, a supplemental insurance, and insurance through her husband's retirement. None of these will cover her. Her family feels they should have hid money before this so she could get

Medicaid like the "other smart people do". They do not see that this money was saved to provide comfort for old age and not as an inheritance for them. They cannot help that they think this way because this type of thinking has been ingrained in certain people for a long time. Success has meant that when one dies, one leaves an inheritance. No one dreamed of the phenomenal cost of long term care or the increased life span we now have due to medical advancement.

Mrs. H. is a proud lady. She has been in the care of her daughter for many years, but her daughter is getting old and can no longer provide care. Mrs. H. has worked hard to provide for herself in her old age through farming. She held a great deal of property which some years ago her son stole from her. Her daughter has protected the remainder of her money, but it has run out and they are now applying for Medicaid. Mrs. H. is devastated that she must rely on charity in her old age and has been crying a great deal. Her daughter is angry with the attorney who set up the original contract with her brother and mother. She believes he purposely set out to cheat her mother. In order for her mother to get the money, she must travel to her home state, and testify at a trial. Her attorney feels that because of the technicalities in the contract, the jury will want to question Mrs. H. Her physician rightly feels Mrs. H. cannot stand the strain of the trip or a trial. Her daughter estimates that the brother owes her mother $75,000.00 in interest and payments. There is nothing that can be done to get her money and she must get assistance for her care. She does not see how deserving she is of this assistance. She paid her way throughout 92 years of life, supported this country, and helped to give all of us the lifestyle we enjoy today. Due to the negative perception associated with the Medicaid Program, she and her daughter feel less than they are. What can I say to them?

Mrs D. is 48 years old. Her husband has Huntinton's Chorea and she has cared for him at home for 6 years. He has been with us for 3 years and could live another 6-7 years with good care and no complications. They have five children. Mr. D. was a veteran so they are getting some assistance through the VA. Mrs. D. works full-time as a school secretary to help augment her income. Things were very tight until about one and a half years ago when her 21 year old daughter was killed by a drunk driver. She received an insurance settlement. She cries that her daughter had to die for her to afford the cost of her husband's care. If he lives long, most of that money will be gone. What will she do when she needs help later in life? Her future looks very insecure.

Mrs. G. came to my office about her husband. She is an 82 year old frail, sickly woman who looks ten years older due to the strain she has been under for five years. Her husband has Alzheimer's Disease. He had been driving their car to Georgia and

Disney World, turning on stove burners in their mobile home during the night, and giving away money of which they had little. She did not place him in the nursing home because she did not have the money. On the night Mr. O. was finally admitted to us from the hospital, he destroyed a geri-chair in a combative rage and had to be sedated. This had been normal for him at home this past five years, and Mrs. O. lived in fear. Mrs. O. discussed their finances with me and I suggested she apply for Medicaid. Mr. O. died this past weekend. Mrs. O. had been living on an income of $250.00 a month which was to be increased this month. She was frequently ill, unable to drive, and received help from her family to survive. She spoke frequently about the fact that she was unaware of the Medicaid program or she would have placed him sooner in the nursing home. There are many Mrs. O's in the community who are trapped in their homes, unable to provide care, having little family support, and ignorant of the way out.

One day, an old woman called me on the telephone crying. She said she was 86 years old and trying to take care of her 84 year old sister. She told me her sister wouldn't eat and she had a bedsore that was getting worse. I asked if she had been to a doctor and she said she could not get her to one. After I got her doctor's name, I called him. That same day he went to their home and decided to admit Mrs. B. to the hospital. Her sister, Miss T., came to see me about placement because the doctor said she could no longer provide care for her sister. She told me that she had been taking care of her sister as part of an agreement. Because she only had a social security check and her sister had a home and savings, it was decided that Miss T. would provide care in exchange for a place to live. Mrs. B. was diagnosed as an Alzheimer's victim. After admission to the facility, Miss T. visited her sister daily. She would cry after her visits and I tried to determine the cause. She finally told me that she should have put her sister in the nursing home long before she did, so she could be comfortable and receive appropriate care. She also said she could never forgive herself because she lost her temper with Mrs. B. and sometimes hit her because she refused to do what she asked. Mrs. B. died and her sister carries the guilt with her to this day.

How many people are like Miss T.? How many are old, isolated in the community, dealing with the stress of providing 24 hour care for an Alzheimer victim, fearing the loss of income and security that would accompany long term care placement, and living with the guilt, when their human tolerance level is surpassed? Who can blame Miss T.? Whose fault is it? The daughter up north had no idea how badly conditions had deteriorated and perhaps, was foolish to think Miss T. was capable of providing care. An aide had been hired to help with the bathing and care and was at the home two times a week. Neighbors later stepped forward and said they suspected problems. The priest who visited often suggested long term care placement. Yet, no one reported these conditions to agencies who could have helped - before this sweet, fragile woman had to live with the guilt from her very human reaction to a life of hell. Would the existence of a custodial care insurance policy have helped to make a better decision? Would public awareness programs have helped?

I have given you a representative sample of the cases with which I deal. My role in a long term care facility is as an advocate for families and patients. I am employed in the health care field, a free enterprise, profit-making industry. I represent the patients I serve today and I fear for my own future as a member of the ever-aging Baby Boom. What does our future hold? With the shift in population that is occuring, will we have an adequate tax base to support the growing number of older people in this country and the cost of their health care? The theory behind supporting a profit-making health care industry is that doing so makes health care cost effective. However, costs are rising each day. The nursing home industry quotes an average profit margin of 6-7%[1] which is certainly not exorbitant. Salaries for the majority of health care workers are low in comparison to other industries. Do we deviate from a basic premise of the free enterprise system and support socialized medicine as is done in other countries? Will the American people accept the loss of choice involved with this system or pay the high taxes which go hand in hand with socialized medicine? Is Florida showing us what the future holds for our nation as predicted in Megatrends?[2]

Whose responsibility is it to fix these problems? I stated it was everyone's responsibility and I would like to make suggestions which elaborate my point.

First, we must make a massive effort to educate the public. We each have the responsibility to shoulder the cost of long term care. We must advise Americans to do financial planning. Married couples should divide assets prior to illness so that each person is protected. They should use those funds for care, if needed, then apply for assistance. Sons and daughters should no longer think in terms of inheritance, but should use monies their parents saved for their old age to provide care. This will ease the burden to all taxpayers and let us care for people who were not fortunate enough to have money at the end of their life. When the money is gone, the stigma of being on Medicaid should be erased. Each and every person in this country deserves help when their resources are gone. The community should be made aware that this help exists to prevent some of the misery that is now happening. When I speak to most families, they are unaware of the programs in existence today.

Secondly, we must educate the professionals who are trying to help these patients. This includes, hospital social workers, nursing home social workers, attorneys, physicians, and home health care agencies. I have spoken to representatives of each area and none of them - no matter the number of years in the business - completely understand the system and help that is currently available. A resource book should be prepared by each state's health department with all of the private, federal and state financial assistance available to long term care patients. This book should include criteria for participation, amount of financial assistance and contact people for each resource. Most social workers find out about this information haphazardly through word of mouth, or hundreds of phone calls. If such a book now exists, I am unaware of it and so are the people with whom I have spoken.

Thirdly, we could consider the elimination of clauses , i.e. "3 day hospital stay", "within 30 days of discharge from hospital" in Medicare and insurances so that whenever a patient requires skilled care during his illness, the insurances can begin helping. Skilled care is skilled care. Why should Medicare have to pay for another hospitalization if the procedure can be done in a long term care setting? Why should a patient be penalized because he doesn't deteriorate within 30 days of leaving a hospital? Also, we should eliminate clauses requiring approval from agencies other than state and federal. In this way, some of the insurance for which people have been paying will be used.

Fourth, we should offer incentives to private insurances to provide custodial care policies. They could pay a portion or all of the bills. Insurance companies are for profit also, and the cost of long term care is expensive. However, premiums could support a custodial care program due to the low probability of need for long term care in relation to the general population who would be willing to pay these premiums.

Fifth, we must increase the income limit for Medicaid assistance, so that those who fall in the grey area between qualifying for Medicaid and affording the cost of long term care are given the help they need. Any person whose income falls below the average cost of long term care should receive finanacial assistance. Florida's income limit does not even meet the federal limit due to our high concentration of needy elderly. Perhaps states should be federally subsidized on the basis of need and statistical projections so that they can at least afford to meet federal guidelines, which I might add are too low.

Lastly, in Florida at least, the days of the "County Old Folks Home" are gone. This has been hailed as a major achievement in health care. However, we have no place for the people who do not have the resources to get care. I do not advocate shipping these people off to a facility for the poor, but perhaps the system we have now can be utilized. Incentives could be offered to existing long term care facilities to keep these people. If we can offer incentives to other industries in this country, why not to the industry which will eventually affect every American?

I used to be a bank teller. The pay was low, but I served my customers. I always came up with the right answer, my work was done at the end of the day, and if I had a problem, I could easily find an answer - everything balanced. Today, my work is exhausting. I deal with problems that have no answers. I can't always serve my customers. There is no balance - no fairness. I could probably make more money elsewhere, but I love my work. I steer people through some of the most devastating crises of their lives by offering support, understanding and guidance. I need the tools to fix their problems. You have the power to give me the tools. I do not presume to understand the economic structure of this country, nor do I presume to have all the answers. I do not represent anyone except the people I am trying to help - the families, the patients, and the other professionals who are frustrated and in despair. I fear for their future and I fear for my own.

Footnotes

1. Steve Rogers, "Creating the Continuum at Care Enterprises," Contemporary Long Term Care, January 1986, p.30

2. John Naisbitt, Megatrends: Ten New Directions Transforming Our Lives, (New York, Warner Books, 1983), p. 207-259

Mr. **Waxman**. Thank you very much for your testimony.

Mr. Mackall.

STATEMENT OF WILTON B. MACKALL

Mr. **Mackall**. Chairman Waxman, welcome to the sunshine State of Florida.

Mr. **Waxman**. Now wait a minute—I am a Californian where it is 80 degrees.

Mr. **Mackall**. That is why I was welcoming you to Florida. And Congressman Bilirakis welcome home from your trip to Viet Nam.

My name is W.B. Mackall. I am a special assistant to the director of the Medical Center at Bay Pines. On behalf of the patients, the employees, and the volunteers at the Medical Center I wish to express my appreciation for the invitation to be with you this morning.

Our testimony addresses programs at Bay Pines and does not represent the entire VA system. Having been involved with veterans' programs and eligibility for the past 40 years, I am also aware generally of the medical care and benefit programs of the Veterans' Administration.

The VA Medical Center at Bay Pines consists of 670 beds, 240 nursing care beds, 200 domiciliary beds and an outpatient clinic at Fort Myers, FL. It serves 10 county areas of Florida's west coast with a veteran population of approximately 250,000. Bay Pines treats over 10,000 in-patients per year and accomplishes 160,000 outpatient visits. The outpatient clinic in Fort Myers performs an additional 35,000 outpatient visits annually.

The medical center provides comprehensive medical, surgical, and psychiatric and rehabilitative services and has specialized programs in alcohol treatment, mental hygiene, respiratory care, and hospital-based home care. The medical center also provides community nursing home care and other community health care services and serves as a clinic of jurisdiction for the entire State of Florida.

In recent years, because of a major replacement hospital construction project, nursing, domiciliary, and medical surgical facilities at Bay Pines have been added or replaced. The third phase of this project will be completed within the next few months and includes the remodeling of two existing buildings to replace psychiatric beds and administrative office space.

This full range of acute and extended care programs is available to all eligible veterans in established priority order. In general, provisions of law and regulations require the administrator to satisfy the medical needs of patients in descending order of priority from the treatment of a service connected disability to the treatment of medical conditions of patients whom service connection or eligibility have not yet been established.

Victims of Alzhemer's disease are afforded the same degree of access to medical care at Bay Pines as are those suffering from other debilitating disease. Placement in institutional or noninstitutional care is determined through physical examinations and assessments of many factors, such as diagnosis, prognosis, stage of the disease, degree of disability of the patient, availability of care providers, and so forth.

Once the level of medical care needed is determined the legal requirements of VA service are applied to establish eligibility for care by the VA. As there is no cure or prevention for Alzheimer's disease, Bay Pines provides evaluation and diagnosis for the patient and support and education for the patient and family in managing the social problems that arise.

A hospital home care program and community services assist in maintaining the patient in the community. It is generally held that it is best for the patient to be maintained at home in a familiar environment or in the least restricted environment for as long as possible.

As the disease progresses, either hospital or VA nursing homes or community nursing homes may be required and appropriate placements are made, again, depending on eligibility and available resources. It should be noted that the VA is not authorized by law to provide unlimited care.

For example, we can only place nonservice connected patients in community nursing homes for a maximum of a 6-month period following VA hospitalization. Over the next 10 or 15 years steady increases in the need for both inpatient and outpatient care is projected because of the rapid growth in Florida's veteran population and because of the increasing age of that population.

Through the department of medicine and surgery medical district initiated program planning process, there are local, district and regional efforts to objectively identify and plan for the current and future medical needs of this elderly patient population.

Dementia, including Alzheimer's disease and other disorders, is one focus of the VA's planning to meet the needs of the geriatric patient. During recent years the VA has sponsored several initiatives in research, education and clinical care that specifically addresses the challenge of Alzheimer's disease and related dementing illnesses.

These initiatives include programs of basic biomedical and applied clinical research and development of specialized clinical programs, and the presentation of education and training programs that focus on the diagnosis and treatment of Alzheimer's disease.

In fiscal year 1984 the VA funded 124 studies of Alzheimer's type and other dementias. Clinical care programs, including the VA's geriatric research, education and clinic centers, known as GRECC's, some of which have developed special units for the diagnosis and treatment of Alzheimer's disease.

In addition, approximately 50 VA medical centers have developed geriatric evaluation units, GEU's, that provide comprehensive assessment for elderly patients, including patients with dementia illnesses.

Please be assured of the VA's continuing commitment to meet the needs of our growing elderly veteran population. I and the members of the medical staff want to thank you and the congessional committee for your support of the Veterans' Administration.

I will be glad to answer any questions.

[The prepared statement of Mr. Mackall follows:]

STATEMENT
OF
WILTON B. MACKALL
SPECIAL ASSISTANT
TO THE
DIRECTOR
VETERANS ADMINISTRATION MEDICAL CENTER

My name is W. B. Mackall and I'm the Special Assistant to the Director of the VA Medical Center, Bay Pines, Florida. On behalf of the patients, employees and volunteers of the VA Medical Center, Bay Pines, Florida, I wish to express my appreciation for the invitation to be with you this morning. My testimony addresses programs at Bay Pines and does not represent the entire VA system. Having been involved with veterans programs and eligibility for the past forty years, I am also aware generally of the medical care and benefit programs of the Veterans Administration.

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Victims of Alzheimer's Disease are afforded the same degree of access to medical care at Bay Pines as are those suffering from other debilitating diseases. Placement in institutional or non-institutional care is determined through physical examination and assessment of many factors, such as diagnosis, prognosis, stage of the disease, degree of disability of the patient, availability of care providers, etc. Once the level of medical care needed is determined, the legal requirements for VA service are applied to establish eligibility to care by the VA.

As there is no cure or prevention for Alzheimer's disease, Bay Pines provides evaluation and diagnosis for the patient and support and education for the patient and family in managing the social problems that arise. A hospital based home care program, and community services assist in maintaining the patient in the community. It is generally held that it is best for the patient to be maintained at home, in a familiar environment or in the least restrictive environment for as long as possible. As the disease progresses either hospital, VA nursing home, or community nursing home may be required and appropriate placements are made, again depending on eligibility and available resources. It should be noted that the VA is not authorized to provide unlimited care. For example, we can only place non-service connected patients in community nursing homes for a six-month period following VA hospitalization.

Over the next 10 to 15 years a steady increase in the need for both inpatient and outpatient care is projected because of the rapid growth in Florida's veteran population and because of the increasing age of that population. Through the Department of Medicine and Surgery's Medical District Initated Program Planning process, there are local, district and regional efforts to objectively identify and plan for the current and future medical needs of this elderly patient population. Dementia, including Alzheimer's Disease and other disorders, is one focus of the VA's planning to meet the needs of the geriatric patient.

During recent years the VA has sponsored several initiatives in research, education and clinical care that specifically address the challenge of Alzheimer's disease and related dementing illnesses. These initiatives include programs of basic biomedical and applied clinical research, the development of specialized clinical care programs, and the presentation of education and training programs that focus on the diagnosis and treatment of Alzheimer's disease. In FY-1984 the VA funded 124 studies of Alzheimer type and other dementias. Clinical care programs include the VA's Geriatric Research, Education and Clinical Centers (GRECCs), some of which have developed special units for the diagnosis and treatment of Alzheimer's disease. In addition, approximately 50 VA medical centers have developed Geriatric Evaluation Units (GEU's) that provide comprehensive assessment for elderly patients including patients with dementing illnesses.

Please be assured of our continuing committment to meet the needs of our growing elderly veteran population and,
I and the members of our medical center staff want to thank you and the Congressional Committees for your support.

Thank You.

Mr. WAXMAN. Thank you very much, Mr. Mackall.
Mr. Arnold.

STATEMENT OF HENRY A. ARNOLD

Mr. ARNOLD. Good morning Chairman Waxman, ladies and gentlemen.

I am Henry A. Arnold, a senior vice president of Gulf Group Services. You may know the company better as Gulf Life Insurance Co. I appear before the subcommittee today, however, as State chairman of the Health Insurance Association of America.

The HIAA is a national trade association comprised of 355 insurance companies which underwrite approximately 85 percent of the health insurance currently sold in the country. The health insurance industry is very concerned about Alzheimer's disease, its impact on its victims and their families and its financial implications to the health insurance industry and the insurance-buying public.

We are especially sensitive to the need for long-term custodial care. Now the HIAA is grateful for the opportunity to share with you today our views and concerns with regard to Alzheimer's disease, particularly as they relate to cost and financing.

Most of the insurance industry recognizes that Alzheimer's disease is in fact a progressive organic brain disorder, and while it affects memory, mood and personality, we do not categorize it as a mental disorder under the mental and nervous provisions of most insurance policies.

Our statistics show that over 1½ million Americans are victims of Alzheimer's disease and that it contributes to approximately 100,000 deaths per year in this country.

HIAA members recognize that caring for the Alzheimer's victim is very stressful and can lead to frustration, anger, confinement and depression for both the victim and the caregiver. Although the home is the preferred caregiving setting, sometimes a family becomes unable to continue home health care.

The decision that a loved one must be placed in a long-term care facility is a difficult one to make and the financial responsibility can be catastrophic. Long-term care can mean more than just a protracted stay in a nursing home.

It is a complex area of need which includes a variety of medical and nonmedical services. The cost of these services is an emerging concern of the elderly in the wake of heightened sensitivity to their potential risk of requiring some type of long care services.

Presently, most HIAA members view the issue of payment for Alzheimer's disease and related disorders in the same manner as any other diagnosis category. Most indemnity policies, regular insurance policies, allow payment of charges for physician's services, drugs, covered medical supplies and routine outpatient care.

In fact, over the last 2 years there is an emerging concentration on outpatient care and paying outpatient care at a higher percentage of reimbursement than inpatient care. But traditionally, however, basic health insurance policies specifically exclude custodial care and therein lies the problem.

While insurance companies have been responsible for reimbursing somewhere around 70 percent of inpatient care in this country, we recognize that the insurance companies have paid something less that 2 percent for nursing care coverage.

This long-term custodial care is excluded for a number of reasons, or has been traditionally in the past. It is very expensive. It is very difficult to project costs for long-term custodial care. It is very difficult to assess risk. It is not a well-defined expense in many cases.

However, in the last 2 years insurance companies have made significant strides in providing coverage for long term care to combat the rising cost of inpatient care. Most of this effort has been directed toward coverage in lieu of inpatient care.

However, our activity in this area has provided us with protocol, with administrative procedures to deal prospectively with these kind of costs. For example, in my own company we conduct utilization review prospectively, in advance of a claim being incurred. One of the problems that we are encountering is finding alternative delivery systems.

For example, home health care. We typically use nonskill facilities whenever we can to discharge patients from the hospital early. One of our problems is finding home health care services to fill that need. Our other problem is a certificate of need requirement in the State of Florida which extends to home health care agencies as well as to the acute care facilities.

We think that there should be some mitigation of that bureaucratic process. The long-term nature of getting a certificate of need filed probably should be eliminated for these kinds of agencies so they can be licensed as home health care facilities so that the insurance companies, prospectively, when a physician submits a plan in advance, will be able to find the resources to bring into the home, where we think the care should occur, those unskilled or intermediate skilled people who can assist the family in care of the patient.

[The prepared statement of Mr. Arnold follows:]

STATEMENT
of the
HEALTH INSURANCE ASSOCIATION OF AMERICA

Good Morning, Mr. Chairman and Members of the Subcommittee. I am Henry A. Arnold, Regional Vice President of Gulf Group Services Corporation, a wholly owned Subsidiary of the American General Corporation, which is headquartered in Texas. I am the Florida State Chairman of the Health Insurance Association of America (HIAA).

I appear before this Subcommittee today on behalf of the Health Insurance Association of America (HIAA). The HIAA is a national trade association comprised of 335 companies which underwrite approximately 85% of the private health insurance currently sold in this country.

The health insurance industry is very concerned about Alzheimer's Disease, its impact on its victims and their families, and its financial implications to the health insurance industry and the insurance-buying public. We are especially sensitive to the need for long-term custodial care. The HIAA is grateful for the opportunity to share with you today our views and concerns with regard to Alzheimer's Disease, particularly as they relate to health care costs and financing.

OVERVIEW

Alzheimer's Disease is a progressive organic brain disorder affecting memory, mood, personality and, eventually, physical functioning. Over 1.5 million Americans are victims of Alzheimer's Disease and it contributes to more than 100,000 deaths annually.

HIAA members recognize that caring for the Alzheimer's victim is very stressful and can lead to frustration, anger, confinement and depression for both the victim and the caregiver. Although the home is the preferred caregiving setting, sometimes a family becomes unable to continue home health care. The decision that a loved one must be placed in a long-term care facility is a difficult one to make and the financial responsibility can be catastrophic.

Long-term care can mean more than just a protracted stay in a nursing home. It is a complex area of need which includes a variety of medical and nonmedical services. The cost of those services is an emerging concern of the elderly in the wake of heightened sensitivity to their potential risk of requiring some type of long-term care services.

COVERAGE FOR ALZHEIMER'S DISEASE AND RELATED DISORDERS

Presently, most HIAA members view the issue of payment for Alzheimer's Disease and Related Disorders in the same manner as any other diagnosis category. Most indemnity policies allow payment of charges for physician's services, drugs, covered medical supplies and routine outpatient care. Traditionally, basic health insurance policies specifically exclude custodial care.

Long-term custodial care is excluded in most contracts because it is extremely expensive. Simply put, no one wants to allocate enough scarce resource dollars to pay for the projected expense.

Nursing home expenses are the largest single out of pocket health care expense faced by the elderly. It has become increasingly clear in recent years that neither federal nor state government will be able to provide the long-term care services needed by our nation's growing elderly population. Medicare and Medicaid, the two programs that would normally assist the elderly, are already being restricted as part of federal deficit reduction efforts, and will not be significantly expanded. Consequently it has fallen to the private sector to undertake the difficult task of underwriting expanded and different forms of long-term care coverage.

WHAT IS LONG-TERM CARE INSURANCE?

Long-term care insurance is private insurance which supports a variety of health and social services for older Americans, including nursing home care. Long-term care policies provide different lengths of coverages and different types of nursing home benefits. Some policies provide coverage only for short stays in nursing homes. Other policies provide coverage for longer stays of up to three or four years. These insurance policies usually provide different benefit levels in terms of dollars or days of coverage, depending on whether the insured is receiving skilled, intermediate, custodial or home care. (Benefits are designed this way for several reasons. It costs more to receive a higher level of care than to receive a less intensive level of care, and the benefit levels reflect this pricing structure of providers. By providing benefit levels at a fixed amount for each day of covered service, patients and their families are given a reason to find efficient providers who can supply needed care within the benefit level. Thus, limits are placed on an insurer's liability under any one policy, and the risk of providing insurance is somewhat reduced.)

Statistics indicate that in 1982, non-government sources paid for 70% of Americans' hospital costs, whereas private insurance paid less than two percent of nursing home costs. Some feel this indicates that private insurance is not supporting its share of this service.

Many earlier forms of long-term care insurance policies emphasized nursing home coverage over home care for a variety of reasons. Insurance must clearly define the risk covered and should provide coverage designed to avoid anti-selection. Entry into a nursing home is an event which is more easily identifiable and is less within the subjective control of the insured than in the case of home health care. Due to the difficulty of distinguishing among levels of care, some companies limited coverage to skilled and intermediate nursing care. Other companies required custodial or unskilled care to be preceded by a period of skilled nursing care in order to assure that the care received was due to medical necessity. Innovations in the levels of care covered by long-term care policies are now underway, with the offering of benefits for less than skilled nursing care.

Also, it is virtually impossible to predict what the cost of nursing home care and home health care services will be several years in the future when benefits might be used. By focusing on indemnity type benefits, carriers are able to make projections based on a fixed benefit level. In most cases, claims experience under a particular policy takes several years to develop.

As a result of a growing aging population and the escalating costs of public health care programs, there is increasing pressure on both government and industry to play a significant role in providing long-term care benefits to the public.

WHY IS IT IMPORTANT?

With the costs of long-term care escalating, fewer people will be able to finance such services from their own personal resources. The Medicare nursing home benefit, as with private coverage, was designed to pay for acute episodes of illness and is limited to only a 100 day stay. Medicare supports about 45% of all nursing home care in the country.

Because of these factors, it is anticipated that there will be increasing demand for private long-term care products. If the private sector does not respond voluntarily, the federal government or states may mandate the offering of long-term care products and unilaterally define the parameters. One alternative may well be complete government control over long-term care. Under such a scenario, the political demands at that time would determine a lifestyle for those needing long-term care. It is reasonable to expect that long-term care will be perceived as a market opportunity by carriers. Onerous regulation and legislation would inhibit market expansion.

Pressures from the federal and state governments, providers and aging groups have catapulted long-term care into the forefront of health policy issues. There has been extensive coverage on national television networks, in newspapers, professional journals, and in periodicals directed at the business community and the general public. The issue is with us now and will become more pressing.

HISTORY OF HIAA POLICY AND ACTIONS

In 1983, the HIAA completed a two-year study of the social and economic impact of long-term care. Since then, the HIAA has developed a set of principles for the financing and delivery of long-term care services. Industry activity reflects a heightened level of concern among providers, government and aging groups regarding the potential explosive demand for long-term care services as the population ages.

Our industry task force is working hand-in-hand with the National Association of Insurance Commissioners and its advisory group to develop the best environment to actively promote such products. Several meetings have already been held by the NAIC with public and private sector groups, including the Department of Health and Human Services, the nursing home industry, senior citizens groups, and insurers.

The Senate Special Committee on Aging held hearings on the issue in September, 1984, at which HIAA testified. In addition, industry representatives have participated in a variety of public forums. And, a 1984 industry conference on long-term care explored long-term care issues and their relationship to the private health insurance industry.

CAN THE INDUSTRY HAVE AN IMPACT ON THE ISSUE?

Government, the nursing home industry, home health agencies, and the aged have a vital interest in the development of private long-term care products and strategies. If the industry is responsive, there is a strong possibility that it can lead in the development of regulations and legislation that would support the industry.

In 1985, more than a dozen bills were introduced in the states relating to some aspect of long-term care. At the federal level, there is heightened Congressional interest, particularly regarding Alzheimer's Disease.

There are a number of bills which would address various aspects of the long-term care issue. The federal legislation falls into three major categories: 1) tax incentives, in the form of refundable tax credits for long-term care expenses; 2) proposals to institute new home health care services, such a block-grant funding to the states proposed by Senator Hatch (R. Utah); and 3) proposals to expand Medicare/Medicaid coverage for acute and long-term care services for the elderly.

CONCLUSION

Long-term care can require an interrelated array of health and social services. Thus, the issue involves all sectors of the health care delivery system, as well as other sectors providing social support services. It cross-cuts all levels of government and private industry. A tremendous amount of coordination is necessary in order to develop solutions to the problem. Financial considerations are the largest barrier to solving this issue. The fact that many long-term care services are custodial in nature, and that their services may be most in demand, complicates the issue for insurers.

Mr. Waxman. Thank you very much. We'll start with you Mr. Arnold. When you talk about private insurance it does not sound like there is too much available now for people to insure themselves privately for the costs that would be incurred should a family member have Alzheimer's disease. Is that a fair statement?

Mr. Arnold. Currently, and in the past, there has not been too much available other than for the traditional medical coverage which has not been extended for Alzheimer's disease. The problem, of course as I said, is custodial care. It is a problem of scarce resources, Mr. Chairman.

We recognize that there are many requests for coverage that must be included in one package. There are over the last 5 years, last 10 years, many mandated coverages. For example, pregnancy is a mandated coverage for employers' plans. Now, that was a Federal law, Public Law 95-555, which requires that the employer pay for pregnancy.

There are some States that just recently passed laws that require coverage for, I guess it is called in-vitro fertilization. There are laws that require coverage for vasectomies. So——

Mr. Waxman. Are you saying that unless we pass a law to mandate coverage there will not be coverage? Or are you saying that because we mandate coverage in other areas that we cannot——

Mr. Arnold. No, sir; I am saying that part of the problem is there are some mandated coverages that I believe and the HIAA believes were ill-advised. In other words, coverages were for, not for illnesses, but certain——

Mr. Waxman. But if we do not mandate coverage for Alzheimer's disease, if someone were willing to pay for coverage and said, look, I am worried about this disease and I want to be sure that my family is protected from being wiped out economically, I want to buy a policy from you, can you buy the policy from the private sector?

Mr. Arnold. There are policies available in the private sector for long-term or custodial care. They are, by their very nature, limited because of the difficulty you have already heard in testimony, the difficulty of projecting what the expenses will be.

They are limited benefit policies for a certain period of time. You can buy policies from 3 to 5 years that range anywhere from $25 to $85 a month, depending upon the age of the insured.

Mr. Waxman. Are companies looking to change their policies to provide better coverage for home care, respite care and other types of services needed by Alzheimer's patients?

Mr. Arnold. Absolutely.

Mr. Waxman. What will be the cost of this additional coverage of long-term care?

Mr. Arnold. Here are some examples of annual premiums from various insurance companies for long-term care: Age 60 to 64, $250 to $500, that is per year; age 70 to 74, $700 to $1,300. Now, that may seem costly but the alternative, paying out of pocket for nursing home care for private day patients, average costs $2,000 to $2,500 per month.

Mr. Waxman. So we are talking about limited coverage from the private sector. And whatever coverage can be purchased is very expensive and even then limited. We really do not have an adequate way, through either government programs or private programs, unless you have your own personal means, to deal financially with the loss that people are going to have in their family's budget should Alzheimer's strike a member of their family. Is that a fair statement?

Mr. **Arnold**. That is a fair statement, Mr. Chairman. We would agree with that. We are, as the insurance industry, we believe, taking giant steps and starting in 1985 and continuing in 1986 to find a way to underwrite this risk, to get a handle on what the costs are.

We firmly believe that the proper setting for this care is in the home. We have got to find ways that we can project what those costs are. We must have the resources to go to.

We feel that we must go to those in a managed health care environment, either through health maintenance organizations, the provider organizations, where there is a strong relationship between the physicians and the underwriters of the coverage, so that we can look at this care prospectively and make the best possible estimate of what those costs will be.

Mr. **Waxman**. Thank you very much.

Mr. Mackall, we do not have jurisdiction in our subcommittee over veterans affairs, and I am not as knowledgeable as Mr. Bilirakis, who happens to be on both the Veterans Affairs Committee and on our committee. But, as I recall, there are some illnesses that, if they are not service-related, the Veterans' Administration has much more limited coverage.

Now, I would think Alzheimer's would not be a service-related disability. Does that mean that the health care coverage for someone in the VA system is more limited and what kind of limits are there on the VA coverage?

Mr. **Mackall**. Yes, Mr. Chairman, there are some limitations. The service-connected veteran has number one priority but in the case of Alzheimer's, which is non-service-connected, as my testimony indicated, they get the same type of treatment when they come into the hospital.

The hospitalization is open to all veterans whether they are service-connected or non-service-connected. It is the outpatient care where we run into the problem.

However, the veteran that comes to the hospital for hospitalization can be treated on an outpatient basis if it is medically determined that home care treatment might obviate hospitalization. You can apply that to any condition, whether it be a heart condition, Alzheimer's, or whatever.

One thing that we can do with the Alzheimer's patient who is admitted to the hospital, and the law says they must be admitted to the hospital before we can take the next step that I am going into, is that after a period of hospitalization we are permitted under the law to outplace the patient either in a skilled nursing home if that is the level of care that the patient needs—and we have 220 of those type beds at Bay Pines—or, if it is custodial type care that the patient needs—and that again is a medical decision—we can outplace that patient into a community nursing home.

We can pay the bills up to 6 months. Now, you say, what happens after that 6 months?

Mr. Waxman. What happens? That would seem like a fairly short period of time.

Mr. Mackall. Well, when you are paying $1,500, $1,800 a month for some 100, 125, 130 patients from your own facility that are in the community nursing home, it is a lot of dollars. However, the Veterans' Administration, through the Department of Veterans' Benefits, has a pension program and assigned to this program is a thing called housebound or A&A. Now, A&A means aid and assistance.

A veteran that has limited income and is drawing pension can draw, with one dependent, up to $642 a month. However, if this patient becomes ill with Alzheimer's and is placed in a VA facility for care and treatment and then is outplaced into a community nursing home for up to 6 months, the Veterans' Administration Department of Veterans' Benefits is allowed—because he or she is a member of that nursing home—to increase that amount to $936 a month.

In many cases, the average income of a couple with Social Security and possibly a small annuity is around $1,200 or $1,300, maybe $1,400 a month. That in itself would almost take that veteran out of the picture of being eligible for this A&A benefit.

But because the House Veterans Affairs Committee, on which Mr. Bilirakis serves so capably, has made it possible that the nursing home care after the 6 months, where the patient becomes a private pay patient, that a letter from the nursing home to the VA that he or she is in a nursing home, completely—and that the cost we will say is $1,500 a month, which I realize is low, but it is $1,500 a month, the $1,500 a month income that they have is wiped out because it is being paid to the nursing home for the care of the patient.

On top of that there is $11,240 annually can be paid to that veteran or to the wife, who is the caretaker of the patient, that works out to $936 a month. Medically they say that the patients should be at home as much as possible. That patient who is at home could be a housebound patient and that housebound patient would go from $7,700 annually to $9,000, or $751 a month. The housebound benefit can continue until death.

The aid and attendant benefit can only remain as long as the patient is in a nursing home, or if the patient goes home—as the gentleman here said that he took his mother home—if the patient is unable to feed himself, clothe himself, take care of the necessary needs of nature, and is so documented by a physician, then that aid and attendant benefit can continue while the patient is at home.

Mr. Waxman. It sounds like the Veterans' Administration has a much more generous coverage for its members than Medicare has for most elderly people. Is that an accurate statement?

Mr. Mackall. That is a good statement, Mr. Chairman.

Mr. Waxman. Now, does Medicare contribute to a veteran or is this——

Mr. Mackall. No sir; Medicare does not contribute anything to the VA.

Mr. Waxman. Well, perhaps we might look at the VA to see how well their coverage might fit in under the Medicare Program. Do you think there is a model that you all can look at and see if we ought to extend coverage for Medicare beneficiaries to be the same?

Mr. **Mackall**. Yes, sir; I really do believe the latter. I feel so helpless in many, many instances for people who come to our hospital and our office just for advice about what can I do with dad or mother, or what can I do with my brother. They are nonveterans. It is devastating, Mr. Chairman, to try, as the lady on my right—you want to cry because there is no answer.

I mean all the evidence is not in and nobody has the answer to what am I going to do with mother, what am I going to do with father. The VA, we do have some answers—we do not have them all. We just have some. And thank God that we do have just some of those answers, Mr. Chairman.

Mr. **Waxman**. Thank you.

Ms. Szumski, we mentioned earlier that Mr. Bilirakis has led the recent efforts to include a provision in legislation now before the Congress that would require the Department of Health and Human Services in Washington to establish Alzheimer's family support groups in institutions such as yours. I supported this effort because it is clear to me just how important these groups can be in dealing with the many problems associated with Alzheimer's.

I assume that Bay Tree Nursing Center has an Alzheimer's family support group. How do they function and what kind of role do they play in the lives of these Alzheimer's families?

Ms. **Szumski**. We do not have our own support group at our facility. The family service centers in the area here have been running fabulous family support groups and we have been referring to them. They have more expertise than I could ever have of the illness.

The biggest support I have been able to give to families who come to me is informing them of resources, informing them of aid and attendance programs through VA, informing them of services that are in the area. People are totally unaware. They hide and stay in their homes. They are trapped. They do not get out. They are afraid to ask. They are ashamed. They are guilty, whatever feelings they have.

We are doing a good job toward getting that information out to people but we need to work harder and do more.

Mr. **Waxman**. In your experience do these support groups really make a big difference to the people who use their services?

Ms. **Szumski**. Oh, yes; the support I give—I have 120 patients in my facility I have to give support 1 to 1 to each of those families. I cannot give them 40 hours a week or 60 or 50, enough support. And I cannot give them the kind of support they really need. They need to be with others who have the same problems. I can only empathize. I have not been there.

Mr. **Waxman**. So, while we are talking about the great costs of dealing with the Alzheimer's problem, and we have got to start tackling it, the least we ought to have available to the family members are these support groups to help them through this difficult time?

Ms. **Szumski**. They do a great service to all of us.

Mr. **Waxman**. Thank you very much.

Mr. Bilirakis.

Mr. **Bilirakis**. Thank you, Mr. Chairman. Ms. Szumski, I too am very appreciative of your caring attitude. I am convinced that you do and we appreciate everything that you do for our people.

Mr. Mackall, Mack, you have been a great proponent for veterans in the years that I have been involved with Bay Pines and directly with you and we appreciate all your help in so many very different ways. Your testimony, and I know from my personal knowledge, indicates that the VA is conducting research on Alzheimer's. Where is this research being conducted, Mack?

Mr. **Mackall**. Dr. John Mathers, the ACMD for extended care at the VA central office, has the center where these are being conducted. As I know, the GRECC's that are going on now, there are five of those around the country that are working in the geriatric area and in Alzheimer's.

Mr. **Bilirakis**. Are they actually being conducted in VA facilities or are we talking about VA grants to non-VA?

Mr. **Mackall**. No; in VA facilities.

Mr. **Bilirakis**. In VA facilities?

Mr. **Mackall**. Yes, sir.

Mr. **Bilirakis**. Is that research, or the results of that research, being correlated, or shared, with other research facilities, other non-VA research facilities that might be doing research on this subject, to your knowledge?

Mr. **Mackall**. To my knowledge, I would have to say, yes. I believe that all medical schools and all of the research that is going on in this country today is being shared with one another. But to give you a positive just who is sharing what with whom, I cannot, Mr. Congressman.

Mr. **Bilirakis**. Should there maybe be some sort of clearing house available possibly, Mack, that all these would have to be shared with?

Mr. **Mackall**. Absolutely.

Mr. **Bilirakis**. Thank you.

Mr. Arnold, what can Congress—well, first of all, you are here on behalf of the Health Insurance Association of America, so you are not directly representing your company. In that connection, assuming that the health—and, by the way, I express my appreciation for your willingness to come to testify at this hearing and driving the distance, I believe you have come all the way from Jacksonville for it, and we very much appreciate that, sir.

The hearing, I think, would be incomplete were the insurance industry not included. Can I assume that the insurance industry accepts the fact that there is going to have to be better coverage for long-term care and Alzheimer's?

Mr. **Arnold**. Congressman Bilirakis, that is absolutely correct. There are market demands already because we have, as we all realize, an aging population. That is going to become the market of the future, quite frankly, for insurance companies. We are already feeling those demands and we are developing innovative ways to project the costs for long-term custodial care.

Mr. **Bilirakis**. All right. Now, can Congress be of any help in sort of speeding up these projections so that we can expand the coverage?

Mr. ARNOLD. We have already met with Congress in 1984 and we would like to continue that kind of dialog so that we can express some of the problems that we are having as an industry in developing these kind of products, given the scarce resources that we have to work with.

Mr. BILIRAKIS. Well, Henry, I think by now certainly the insurance industry and others know that I am a free enterpriser and I do not think the Government ought to be involved any more than we might have to be. But where there are needs and free enterprise does not, within a reasonable period of time, take care of those needs—and I am talking about needs for people who cannot help themselves—then Government supposedly would have to get involved.

So, I guess basically what I am saying is that I am talking about catastrophic coverage under Medicare. And I will tell you that there is talk in the Congress for some sort of a catastrophic insurance type of a situation. In my mind, catastrophic would be including long-term care.

I will tell you that the move in Congress, to my way of thinking, is to basically force this issue, if it is not taken care of somehow by the insurers themselves. I would like to commend to your attention, sir, that I would like to see better progress toward that end from the insurance companies themselves.

I just do not want to see the situation arise where Congress is basically shoving somehow, if it is within our jurisdiction, shoving it down the throats of insurance companies, but it may come to that basically to get results.

No threat. Please do not take it that way. I am just trying to be helpful.

Mr. ARNOLD. Mr. Congressman, we are realists, we are very pragmatic, we see that and we see it as a threat, quite frankly. I have been in the business since the advent of Medicare. We see that a lot of Medicare coverages have been cut back and it has fallen upon private industry to pick up the slack where those benefits have been cut.

We recognize that there is a need and we see that the private insurer must fill that need. We are finding ways to do that, as I said. The cost of health care has been ameliorated because of, we feel, a lot of strategies and tactics that insurance companies have developed over the last several years to contain costs.

With that flattening of inflation in health care, we see more dollars being released so that those dollars can be put where they are most needed, hopefully not in vitro fertilizations and those other unnecessary things that have been mandated by regulatory routes, but where they are really needed, in long-term care. It is a very dramatic need and we feel that the insurance industry will fill that need.

Mr. BILIRAKIS. Would you be a good contact for us, sir, should we need any additional information towards this end, so we can help one another?

Mr. ARNOLD. Yes, sir.

Mr. BILIRAKIS. Thank you, sir. And thank you, Mr. Chairman.

Mr. **WAXMAN**. I want to thank each of you for your testimony and your participation in this hearing. You have been very, very helpful to us. Thank you.

The next panel will discuss what can and is being done at the community level to help Alzheimer's victims and their families. Mrs. Josephine Biederman is representing the Alzheimer's Disease Support Group of West Pasco and Mr. William Roberts is with the Area Agency on Aging. These organizations and others like them have been very active as both Alzheimer's resource centers and service providers.

Mrs. Beiderman and Mr. Roberts, I want to welcome you to this hearing today. Your prepared statements will be made part of the record in full. We would like to ask each of you, if you would, to summarize that statement in no more than 5 minutes so we will have a full opportunity to question you.

Mrs. Biederman.

STATEMENTS OF JOSEPHINE D. BIEDERMAN, CORRESPONDING SECRETARY, ALZHEIMER'S DISEASE SUPPORT GROUP OF WEST PASCO, INC.; AND WILLIAM ROBERTS, AREA AGENCY ON AGING FOR DISTRICT V, TAMPA BAY REGIONAL PLANNING COUNCIL

Mrs. **BIEDERMAN**. Chairman Waxman and Congressman Bilirakis, my name is Jo Biederman and my husband has Alzheimer's disease. In 1960, what I thought was the beginning of a nervous breakdown, my husband's personality began to change.

He suffered migraine headaches and in his position of electrical engineer for Westinghouse Electric for 39 years, he suddenly could not interpret intricate blueprints and I believe that this was the formative stage of Alzheimer's disease.

Forced into early retirement at a reduced pension, we still were able to plan to spend a comfortable and active retirement life because we were able to save sufficient funds by making sacrifices in our early married life.

Now these funds are being rapidly depleted, not for a comfortable and active retirement life, but for the catastrophoic expenses of a nursing home. I was able to care for my husband at home while he was ambulatory, although he was not capable of performing the daily normal activities.

I assumed the burdens of daily living for both of us. A hip fracture on October 5, 1984 put him in a hospital and then a nursing home upon his discharge. Postoperative therapy was unsuccessful and my husband can no longer walk, must be fed and bathed, does not talk coherently and seldom recognizes me as his wife of 50 years.

The man I have known and lived with has left me alone. I now visit him every day to feed him and to comfort him with my presence and to be sure he is getting proper care with dignity. After 14 months in this nursing center I was advised by the administrator that my husband was noisy and disruptive to the others and that I had to take action to resolve this matter the same day.

Already under stress, I now faced the problem of taking my husband out in a short space of time. Fortunately, after talking to my husband's neurologist he placed him in the hospital to monitor and evaluate his medication which was believed to be the cause of his disruptive manner.

He is now in another nursing home, much improved and the staff gives time, shows compassion, and are efficient. Nursing home expenses are about $2,000 per month, but $600 is reimbursed from his Westinghouse Electric medical plan. These expenses are paid with 1985 dollars and were funded for retirement and financial security with 1960 dollars.

I find comfort and social activity as a member of the Alzheimer's Disease Support Group of West Pasco. It has helped me understand and how to cope with the problems brought on by his disease. I also attend seminars locally and have gone to Atlanta, GA, and Orlando, FL, at my expense.

I would like to see Federal funds given to our community to set up training courses for staff who care for and have personal contact with the Alzheimer's patient, to encourage local nursing homes to set up special wings used exclusively for Alzheimer's patients and staffed by trained personnel, and to fund existing or new daycare centers for Alzheimer's patients to give respite for caregivers.

I hope that by the testimony you are hearing today you will help us find a cure and lessen the tremendous burdens we are shouldering by passage of the legislation you are currently considering.

Thank you Mr. Waxman and Mr. Bilirakis for giving us hope and thank you for the opportunity to tell you of my experience with Alzheimer's disease.

[Mrs. Biederman's prepared statement follows:]

SUBJECT: Congressional Hearing on Alzheimer's Disease
PLACE: St. Mark Village, Palm Harbor, Fl.
DATE: January 27, 1986
TESTIMONY BY: Josephine D. Biederman, Caregiver
26 Croton Drive, New Port Richey, Fl 33552

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I am Josephine D. Biederman and my husband has Alzheimer's Disease. A simple statement of fact but with complex effects on the lives of the persons involved. I am grateful for the opportunity to testify about Alzheimer's Disease and of the devastating impact it has on the social, economic and emotional health of the victim and the family.

My husband, Loren, was employed as an electrical engineer at Westinghouse Electric Corp. for 39 years. In 1960, at the age of 60, he started to have a personality change from a decisive and calm individual to one who had to exert more effort to make the decision, suffered from severe migraine headaches and had experienced difficulty interpreting intricate blueprints involving a segment of the Niki-Zeus missile project.

I thought he was on the verge of a nervous breakdown, which I now believe was the formative stage of Alzheimer's Disease, and I encouraged him to retire early despite the reduction in his pension benefit to $236.26 per month. Because of our sacrifices in our early married life we were able to accumulate sufficient funds to live a comfortable and active life in our retirement years. We moved to Florida in 1961 and purchased a home and boat and looked forward to a relaxed and pleasant retirement.

Unknowingly, and unfortunately for both of us, Alzheimer's Disease crept into our lives and my husband became very critical of me for no apparent reason, always put me on the defensive, and spoke harshly and rudely to me privately and in public. His illness had started to affect our relationship and I hoped his health would improve. It did not. Our marriage of 32 years up to that time had been a pleasant and normal relationship, and then suddenly in 1967 my husband completely rejected me and from then on I was merely his housekeeper.

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As time went on my husband became more forgetful, impatient, disoriented and incapable of taking care of himself. He became aggressive and one time he almost ripped out my eyes when he scratched my face out of frustration in not being able to understand an explanation about the locking of the door. He was disoriented when driving the car and I had to direct him. It was a blessing when he had an eye operation in 1981 and he voluntarily stopped driving the car. He was not capable of performing the daily normal activities and I had to assume the burdens of daily living for both of us. To satisfy his urge to wander and to avoid getting hurt or getting lost, I walked with him several times a day for approximately one to two miles each time.
During the past several years, starting in 1981, my husband's medical problems increased, beginning with an interoculary lens implant in February 1981; prostate operation in April 1981; stroke in March 1983; diagnosed as Alzheimer's in July 1983; diagnosed as having Parkinson's in September 1983 and a hip fracture on October 5, 1984. Fortunately for us these medical expenses were largely covered by Medicare, supplemental coverage and his Westinghouse medical plan. Until the time of his hip fracture I was able, and capable of, taking care of my husband at home with a minimum of medical expenses and the costs of respite care. Now my husband is completely dependent upon someone else for all his physical needs and as I am no longer able to care for him at home he was placed in a nursing home upon his discharge from the hospital where he was treated for his hip fracture.
Because my husband is a victim of Alzheimer's Disease, post-operative physical therapy was unsuccessful and my husband can no longer walk or talk, must be fed and bathed and seldom recognizes me as his wife. The man I have known and lived with for fifty years has left me alone. There is very little more that I can do for my husband other than be sure he gets the best of care and to comfort him with my presence. I visit him at the nursing center every day to feed him at lunch or I employ someone to substitute for me when I need a day off.

While my husband was at this nursing center, when necessary, I questioned the quality of care that he was getting and made suggestions and requests for changes that I felt would be helpful. Attached to my testimony are two letters that describe some of my hardships during the fourteen months at this nursing center. You can't imagine the emotional shock that I experienced when the administrator of the nursing center came to me in the early afternoon of December 9 to advise me that I had to take some action that day because my husband was disrupting the care center residents by his noisy behavior. I became frustrated and concerned about what action I could take in that short space of time. Knowing that my husband had to be removed from the care center my only recourse was to immediately contact his neurologist and he arranged to have him admitted to a hospital to monitor and evaluate his medication which was believed to be the cause of his disruptive manner. Upon his discharge from the hospital on December 19, 1985 he was placed in another nursing center and is improved. The staff gives time, shows compassion and are efficient in handling their patients.

Mr. Biederman's nursing home expenses are approximately $2,000.00 a month less $600.00 reimbursement from his Westinghouse Electric medical plan. All of my husband's expenses are paid for out of his personal funds which I have set aside in a separate account. We are more fortunate than others but our funds will shortly be depleted. Funds that we set aside for retirement and financial security with 1960 dollars and spending for long term care with 1985 dollars.

When I was told that Mr. Biederman had Alzheimer's Disease I had no idea what it was and what effect it would have on our future. I became a member of the Alzheimer's Disease Support Group of West Pasco and through involvement with their meetings I got educated about Alzheimer's Disease. By listening to medical professionals, social workers, health care providers and most of all listening and exchanging information with other caregivers I was able to cope and adjust my life around this invader to our lives. I have attended seminars locally and in Atlanta, Ga. and Orlando, Fl at my expense. Social activity is stressed among the support group members. I have learned about the care needs of an

Alzheimer patient but I also learned there is a lack of knowledge of this special care. Our support group is privately funded by annual membership dues, private donations in memory of loved ones, donations from the business community and from other organizations We are a self-help group of individuals, organized and staffed by non-professionals who call themselves caregivers. Our support group has underwritten the cost of a self-intructional course, giving continued education units to registered nurses and licensed practical nurses in local nursing homes, which teaches and explains the needs and care of the Alzheimer patient. The course is entitled "Whose Confused" by Linda S. Greenfield, RN, BS. Ironically the practical application of the type and methods of quality care as enumerated in the course is not possible because the nursing home industry is not oriented to this approach.

I would like to see some of the federal funds funneled to our community to help set up training courses for the staff who care for and have personal contact with the Alzheimer patient and to encourage nursing home management to set up a model Alzheimer's Disease patient wing to be used exclusively for Alzheimer patients and staffed by those who have received training in this care.

There is also a need for day care centers who will admit Alzheimer patients to give respite to the caregiver.

As for myself I just live from day to day trying to cope and to try to help other caregivers. My world has narrowed down to coping and living with Alzheimer's Disease.

I appreciate and totally support Mr. Bilirakis' efforts on behalf of the Alzheimer's Disease victim and family and in the hope that by the testimony you are hearing today you will help us find a cure and lessen the tremendous burdens we are shouldering by passage of the legislation you are currently considering.

Thank you for the opportunity to tell you of my experience with Alzheimer's Disease and to express my personal feelings.

26 Croton Drive
New Port Richey, Fl. 33552
April 17, 1985

Ms. [redacted] Administrator
[redacted] Nursing Center
[redacted]
[redacted] Fl. [redacted]

Dear Ms. [redacted]

On Tuesday, April 16, 1985 at 6:20 PM I visited my husband, Loren Biederman in Room 117. I found him in bed, naked and covered with his excrements. He was crying "Get me up. Get me up."

I went to the north station and asked Ms. [redacted] why Mr. Biederman was still in bed after being put there for a nap at 2 PM. Under this condition he could be left in bed for 20 consecutive hours.

Her reply was "Doctor's orders". I advised her that I didn't believe her and I became agitated with her reply.

If Ms. [redacted] was following the doctor's orders she would have seen that he retained his dignity and was washed, dressed and up for his dinner.

When the pool aide came to clean Mr. Biederman she did not know that a spray was to be used each time he was cleaned.

From previous experiences it is known that Mr. Biederman will try to clean the excrements away with his fingers and consequently he has a fungus under his nails which could cause his nails to fall off.

I am patient and understanding and would like to resolve these problems. I try to advise each aide how to cope with Mr. Biederman but I cannot contact all of them when they are constantly changed from day to day. I feel the nurse in charge, who keeps a daily log of the patient's condition and needs, should be responsible for Mr. Biederman's comfort and inform the aides from day to day how to care for their patients.

I expect Mr. Biederman will be a resident for a long time and I hope we can keep him in a comfortable condition.

Sincerely,

Josephine D. Biederman

26 Croton Drive
New Port Richey, Fl.
Zip Code 33552
January 13, 1986

Mr. [redacted] President
[redacted] Nursing Centers, Inc.
[redacted]

Dear Mr. Shive:

Re: Loren T. Biederman
former resident at
[redacted] Nursing Center
from 10/30/84 to 12/9/85

My purpose in writing this letter is to make you aware of the conditions that adversely affected Mr. Biederman's stay at [redacted] Nursing Center, and hopefully that this information may be used to improve the quality of care for other Alzheimer Disease patients now and in the future giving consideration to a separate wing devoted exclusively to Alzheimer Disease patients.

My husband, Loren, suffered a stroke in March 1983 and in July 1983 was diagnosed a victim of Alzheimer's Disease and subsequently was diagnosed as suffering from Parkinson's Disease. During this period of time I was able to take care of him without outside help so long as he was ambulatory. On October 5, 1984 he fractured his hip and was hospitalized until October 30 and and then transferred to [redacted] Nursing Center. At my pre-admission conference with the nursing staff I thoroughly explained what his care requirements were as an Alzheimer patient and was assured he would receive proper care.

During my husband's stay I noticed a gradual decline in his mental and physical health. I attributed the decline to overmedication, a constant change of aides which added to his confusion and with this constant change in personnel there was no set pattern of care from aide to aide. When a male aide was attending to my husband with a degree of compassion my husband responded very favorably to him. But it seems that an aide who showed a little compassion and took time to care did not remain employed very long. For example: Lee Shaw an aide and Jim, an LPN on the 3 to 11 shift. My husband reacted unfavorably to the many changes resulting from rapid turnover of aides and the policy of the nursing director to rotate aides constantly. I believe that the administrative and nursing philosophy is to get the job done as quickly as possible with the least amount of effort. My personal observation also indicated that the high number of intensive care patients, without an increase in aides, diminished the quality care of the other patients.

Re: Loren T. Biederman, continued

I tried to cooperate with the staff and to make it easier for them I purchased a commode to make the switch from chair to commode and then to bed. My husband weighs 165 lbs. and it took two female aides to transfer him. He was actually thrown into bed from the chair or the commode, with the aides falling into bed with him. I think this was uncalled for and demeaning to my husband. For his comfort I also bought a reclining chair at a cost of $473.00.

My husband's medication charges were about $200.00 a month and at times I found items duplicated on my invoice for the month. Specifically he was getting Navane 5mg two times a day. I was billed for 210 pills for the period 9/10 to 10/4/85. This covers a period of 24 day or 48 pills to be dispensed and I was billed for 210 pills. This reflects a laxity in ordering medication. When I called this to the attention of the staff I was told to get in touch with the pharmacy. I think it should have been the responsibility of the staff to make this correction as they have control of the ordering.

On December 9, 1985 at approximately 1:00 PM I was informed by Mrs. [redacted] [redacted], Administrator, that I had to do something about my husband that day as he was noisy and disrupting the other patients. Knowing that my husband was not wanted at [redacted] [redacted] Nursing Center, Iarranged with my neurologist to admit my husband to a hospital to monitor and evaluate his medication as I felt he was being over-medicated and causing his confusion.

As a result of his stay in the hospital my husband's medication was reduced substantially and my first monthly medication charge was $56.00 compared to around $200.00 previously. He is now at Park Lake Village Care Center and he is in a stable condition and is getting friendly and compassionate care from all the staff. The aides are permanently assigned and he is treated with warmth and dignity.

Please accept this letter as a brief history of my unfortunate experience with the care of my husband at [redacted] Nursing Center and is not meant to be vindicative. If it improves the quality of care for Alzheimer patients I feel I have attained my objective.

Very truly yours,

Josephine D. Biederman

Certified mail
Return receipt requested

Medical Expenses - Loren T. Biederman
October 5, 1984 to December 9, 1985

Medical Expenses Hospital, Nursing Home, Medication, Doctors	$45,536
Reimbursed by Medicare and Westinghouse Medical Plan	30,426
Total out of pocket expenses	$15,110
Plus Insurance Premiums and Cost of Respite Care	1,955
Total Personal Costs	$17,065

Mr. WAXMAN. Thank you very much for that testimony.
Mr. Roberts,

STATEMENT OF WILLIAM ROBERTS

Mr. ROBERTS. Members of Congress and ladies and gentlemen, I am Bill Roberts. I am employed by the Tampa Bay Regional Planning Council, which is the Area Agency on Aging for District V, including Pasco and Pinellas counties, FL.

You have already heard that Florida's population is as diverse as any other group and especially the elderly. It is difficult, if not impossible, to stereotype them as a particular group.

There is variety in the group. Let me give you some examples: Eighty percent of Florida's elderly are very active, self-sufficient, and independent citizens within their community. Another 15 percent require some assistance at some time, either on a temporary basis or a partial basis and then they move from that 15 percent back to the 80 percent. The remaining 5 percent do require the needs and services of long-term care that we have heard about this morning.

It is estimated that only 2 of that 5 percent is in Florida's nursing homes. However, nationally we understand 5 percent are in nursing homes. Therefore, we feel that Florida is doing a fairly good job of keeping people out of those long-term nursing home institutions.

However, we want the opportunity to keep adding to our program, adding to the strength to the program. I realize this program is getting along so I will mention only a few of the things that I was going to cover today.

We need to understand the uniqueness of Florida. In 1980 the census listed Florida as the State with the highest percentage of elderly in the entire United States: 23 percent of our population was 60 or over. By 1982, that percentage had already risen from 23 to 25 percent.

In the two counties that I just mentioned, Pasco and Pinellas counties, the numbers increase to 36 percent of their population that is age 60 or over, with over 129,000 that are over 75. So this is a uniqueness that we have to take into consideration in planning the expenditures of the funds of the Older Amercans Act and the Community Care for the Elderly dollars.

There is another unique factor in Florida that we must consider, that many, many of our elderly people move here, migrated from out-of-State. Therefore, they do not have the support system of family, close friends they have lived by for a number of years. This is an important fact we have to remember.

I am very happy to tell you that this last year, 1985, the Council distributed over $6.2 million of Older American Act funds, over $880,000 of USDA funds, and $3.2 million of Community Care for the Elderly funds which are Florida general revenue funds.

To give you some idea of what these funds purchase I would like to give you a few numbers: 322,000 hours were provided in adult daycare programs; 27,000 hours were purchased for chore services; 91,000 days of emergency alert response was provided; 30,000 hours of homemaker service was provided; 516,000 trips to and from dining sites, shopping centers, and doctor visits were provided.

Title III-C of the Older Americans Act provided 800,000 meals at congregate meal sites, 611,000 home delivered meals. Now those were title III funds. In addition to that, the Community Care for the Elderly—the 3.2 million I just mentioned—provided 50,000 hours for daycare, 81,000 hours in emergency alert response, 160,000 hours of homemaker service and 94,000 hours of personal care, plus others. These are just examples that I am giving you.

Florida has adopted a policy of providing more long-term care of the elderly residents. We support that policy. We encourage it. However, the one thing that we do want to remind everyone, at the Federal as well as the State level, remember the 15 percent that I told you that required some service at some time, either partially or temporarily.

If that group is cut by just one-third, if you reduce the 15 down to 10 percent, you could very easily, as Congressman Waxman said earlier, double those needing long-term care from 5 up to 10 percent. So we do need to continue that support for this group, the 15 percent as well as, support for the group in the 5 percent.

I think for the generations that helped this country survive the Great Depression, World War II, Korea, and Viet Nam, we must accept the challenge to provide them with the finest quality of life possible. Thank you.

[The prepared statement of Mr. Roberts follows:]

HOUSE ENERGY AND COMMERCE SUBCOMMITTEE
HEALTH AND ENVIRONMENT
PUBLIC HEARING
PALM HARBOR, FLORIDA
JANUARY 27, 1986

Congressman Bilirakis, members of the Subcommittee, ladies and gentlemen, I am William Roberts, employed by Tampa Bay Regional Planning Council/Area Agency on Aging of District V (Pasco and Pinellas Counties). It is an honor and pleasure to be invited to participate in this public hearing regarding some of the concerns of our elderly citizens.

Florida's elderly population is as diverse as any other age group and can not and should not be stereotyped. Generally speaking, a great majority (80%) of older Floridians are self-sufficient, active members of their communities. Some (15%) are or will become partially and/or temporarily dependent on private or public assistance for basic needs. Many of this group have been able to move back to self-sufficiency with proper private and public support. The remaining group (5%) requires the services of long-term care programs with only two per cent (2%) of the elderly residing in nursing homes. Nationally, it is estimated that five percent (5%) of the elderly reside in nursing homes.

Long-term care is an extremely complex subject involving a wide array of health, social and personal care services ranging across many professional disciplines. The elderly receive services under a variety of authorizations, with different eligibility requirements and administrative structures, in both public and private sectors. In order to provide older people with an accessible, comprehensive system of community-based long-term care, several key components are necessary. These are integration and coordination of community services through resource development and management, and client assessment through a case management system.

Long-term care has traditionally been interpreted as those services provided on an extended term basis to the chronically ill or impaired persons in institutions. As a result, long term care has been commonly viewed as being solely delivered by the medical profession. However, the excessive cost of institutional care and the increased demand for non-institutional community based services by older people and their families have contributed to a growing awareness and acceptance of community based alternatives. Even though the concept of communiy based long-term care is now beginning to broaden, health professionals still tend to view the aging network as providers of services to the well elderly rather than planners and developers of systems of community based, in-home and institutional care services. However, the Network on Aging, via its current structure of State and Area Agencies on Aging, has emerged as the developers and managers of a negotiable continuum of care for older persons and their families in many communities. The mission of the Network on Aging remains to maximize the capacity of older persons to live independently.

At this point it would be appropriate to offer a definition of long-term care. Long-term care is the entire system of health and social services necessary for those individuals who as a result of chronic physical and/or mental illness are experiencing decreased capacity in self-care. It includes preventive, educational, administrative, home-delivered, office or hospital based, day care or respite care and importantly, but not exclusively, institutional care of individuals with impaired capacity for independent living.

Three important factors must be reviewed in any study of long-term care. Those are demographic, humanistic and fiscal factors.

The rapidly growing population age 60 and over nationally is a well known fact and now, one of every nine persons is over age 65. Within 50 years, the aging population will grow from 34 million to 55 million with an especially rapid growth of the very old, those individuals age 75 and over. Nowhere is this growth more evident than in our own state. Florida is the state with the highest percentage of elderly of any state in the United States. The 1980 census reports 23 percent of the state's total population was 60+. The 1982 population estimates have already increased that percentage to 25. Within our own district over 36 percent are aged 60+ with 128,836 over age 75. The aged, below poverty level and those living alone or with a non-relative are additional factors that must be given consideration.

The humanistic factor requires that we recognize that the health care needs and the health experiences of older persons differ markedly from those of the young and of the young adult persons. The health care system now in existence is not geared to the long-term care needs of the elderly. In addition, elderly persons often require the systematic integration of health and social services in order to allow them to continue to function independently despite some chronic disorder.

The third major and most persuasive factor which has commanded national attention is fiscal in nature. Projections of health and long-term care expenditures for the elderly are alarming to politicians, resource allocators and health care providers alike. The cost of nursing home expenditures, some 85 percent of which is for older persons, rose from 7 billion dollars in 1973 to 18 billion in 1979, but more significantly, is expected to rise to 76 billion by the year 1990. Medicaid payments for nursing home care constitutes the single largest and potentiallly controllable expenditure of public dollars.

Community based care, therefore, appears to be the area with the greatest promise of meeting both improved quality of life concerns and reducing costs. Among the alternatives to nursing home care are adult congregate living facilities (ACLF), adult foster care, home care for the elderly, home health, hospice, channeling, communty care for the elderly (CCE) and various programs funded by Title III of the Older Americans Act.

With the changing structure of the family, lower birth rates and longer life expectancy, fewer of the dependent elderly will have such persons to care for them. In Florida, and this district particularly, with the high proportion of elderly who have migrated from out of the state, the likelihood of such support is reduced further.

During 1985 the Council distributed over $6,240,226 in Older Americans Act funds, $879,670 in U.S. Department of Agriculture cash-in-lieu of commodity funds and $3,194,688 in Community Care for the Elderly funds to local agencies for the provision of services to the elderly. Services included adult day care, chore, homemaker, counseling, legal, outreach, transportation, etc. The chart below illustrates the service level provided during 1985 for each program funded under the Older Americans Act and Community Care for the Elderly.

I Funding Source: Older Americans Act

Social Services (January 1, 1985 - December 31, 1985)

Adult Day Care	322,488 hours
Chore	26,835 hours
Companionship	3,538 hours
Counseling	9,428 hours
Emergency Alert/Response	90,613 days
Guardianship	21,298 days
Home Health Aide	3,299 hours
Homemaker	30,355 hours
Housing Improvement	2,483 hours
Legal	15,939 hours
Outreach	12,348 hours
Telephone Reassurance	14,903 calls
Transportation	516,287 trips

Nutrition (January 1, 1985 - December 31, 1985)

Congregate	799,728 meals
Home-Delivered	611,033 meals
Nutrition Education	74,770 hours
Outreach	12,568 hours

II Funding Source: State of Florida General Revenue Funds

Community Care for the Elderly (July 1, 1984 - June 30, 1985)

Adult Day Care	50,280 hours
Case Management	66,533 hours
Chore	13,027 hours
Day Care	50,280 hours
Emergency Alert/Response	81,737 days
Homemaker	160,715 hours
Home Health Aide	2,490 hours
Home Delivered Meals	17,452 meals
Home Nursing	522 hours
Medical Therapeutic	720 hours
Medical Transportation	7,299 trips
Personal Care	94,027 hours
Respite Care	15,331 hours

The recently (January, 1985) published, "Pathways to the Future", the report of the Florida Committee on Aging, recommends two long-term care policies, as follows: Florida will devleop a comprehensive long-term care program including a full range of community care options and pre-nursing home assessment for all elderly considered for nursing home placement. These programs will be designed to ensure the availability of medical and social services needed to meet the long term needs of the elderly in the most cost-effective and least restrictive manner possible. Secondly, Florida will encourage private sector health care providers to become more active in the screening and referral of older clients to appropriate services.

In formulating these recommendations into operating policies, we must not weaken the support system for the 15% mentioned earlier. A reduction of one-third to this group could double the more costly services required for the institutionalized elderly.

For the generations that helped this country survive the Great Depresssion, World War II, Korea and Vietnam, we must accept the challenge to provide them with the finest quality of life in their latter years.

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Mr. **Waxman**. Thank you very much. You have both given us very excellent testimony.

Mrs. Biederman, let me ask you this. Your experience now has been with the support groups. Would it be helpful for your group to have access to a national clearinghouse so it could get information on what other organizations like yours are doing to help Alzheimer's patients and their families? What about access to national information on the places for treatment? Would this be valuable?

Mrs. **Biederman**. It would be very valuable and Ed Geasa of the Tampa Chapter ADRA is very helpful to us in many ways so we do accept that we would like some more national information. Yes.

Mr. **Waxman**. Thank you very much.

Mr. Bilirakis.

Mr. **Bilirakis**. Mrs. Biederman, thank you also for your courage in coming here today. You have had quite a story to share with us. Of course, you are not sharing with the general public a couple of letters that you have written——

Mrs. **Biederman**. No.

Mr. **Bilirakis** [continuing]. To nursing homes here but, we have read them, and are certainly shocked as a result of some of the things that took place. And I thank you for your recommendations as far as Federal funds are concerned.

Mr. Roberts, can we cut from the 15 to 10 percent?

Mr. **Roberts**. No, sir. I am suggesting that if you do cut any of the support from the 15 percent you could very quickly double the 5 percent up to 10 percent. In other words, if you take one-third away from the 15 percent, that is 5 percent. But that 5 percent is not going back into the 80 percent, it is going the other way. It probably would increase the more expensive long-term care needs.

Mr. **Bilirakis**. Are there any areas, any of these funding sources that you are talking about under the Older Americans Act or in general revenue funds, that if in fact—let us say, if there were not additional dollars available—and what we are going through is obvious to everybody right now—if there were not additional dollars available, are there any areas which are being funded now which you feel will be less affected if any of those dollars are shifted?

I am not certainly recommending that but, if something like that were thrust upon us, basically shifting of priorities if you will. This is a high priority to my way of thinking. I mean, we are talking here about an area where people cannot help themselves and families, as much as they try, are still being debilitated and in many cases the spouse, particularly, goes before the patient because of the agony of it all.

Mr. **Roberts**. Let me give you a couple of examples. We now have six daycare sites in Pinellas County. We have two in Pasco County. But one of the six daycare sites in Pinellas County is earmarked for Alzheimer's patients. We are very proud of that and, in fact, the project director for that project is here today. She could probably give you a lot more information about the day-by-day care and treatment.

I am also very happy to announce that starting very soon, in fact, within the next few weeks, this area agency received a $29,000 additional grant from the State of Florida to provide respite care in Pinellas County for families of Alzheimer's patients

So we are already doing some things for the Alzheimer's clients with Older Americans Act and certainly with community care for the elderly. However, when I look at a wagon and you start taking one wheel off of it, it does not move very well with three wheels. We need all of the support system to provide for the needs and meet the needs of the elderly in this area.

Mr. **Bilirakis**. Thank you Mr. Roberts. Thank you Mr. Chairman.

Mrs. **Biederman**. May I make a suggestion?

Mr. **Waxman**. Yes.

Mrs. **Biederman**. I would like to see a wing just for Alzhemer's patients just to see if it could possibly work in Pasco County. Everybody just turns up their hands and says, impossible.

Mr. **Bilirakis**. A wing where, at the nursing home?

Mrs. **Biederman**. At any nursing center, just to have these patients cared for in a proper manner. It would be a wonderful gesture.

Mr. **Bilirakis**. Do we have any nursing home administrators in Pasco County in the audience?

Mr. **Waxman**. Well, rather than have them respond, I think it is a good suggestion and let us have people think about it and respond to it, not testimony, but see if we can get something done.

Mrs. **Biederman**. It would be a dream.

Mr. **Waxman**. Thank you both. You have been terrific people.

For those of you who have seen the agenda for this hearing, this concludes the official testimony we have scheduled.

But I understand that Miss Cathy Lester of the Governor's Alzheimer's Committee of Florida is here to make a presentation and I do not know if Mr. Bilirakis is even aware of this. It may be a surprise. Could Miss Lester come forward?

STATEMENT OF CATHY LESTER, GOVERNOR'S ALZHEIMER'S COMMITTEE OF FLORIDA

Ms. **Lester**. This little bear, Congessman Bilirakis, is a symbol of the love and hugs that we do not get when we are dealing with Alzheimer's and you have to get a hug when I present it.

I lost a husband 4 years and 8 months ago yesterday with Alzheimer's disease.

This little bear is a symbol for Alzheimer's disease. He has a little keychain on him, for the love and hugs that you do not get when you are dealing with Alzheimer's disease. And I get to hug—as a widow, I get to hug people.

We certanly appreciate all the help that Congressman Waxman and Congressman Bilirakis have given the State of Florida in addressing the needs of Alzheimer's people. I lost a husband 4 years and 8 months ago yesterday with this disease and have been through the problems that all of you out there who have a loved one in your home with Alzheimer's are aware of, the years of trying to get an accurate diagnosis. My husband died 2 months into his 63d year and doctors had given me some horrendous diagnoses.

I have done a turnaround. I have gotten past the, why me, to working with the association. I am also the regional director of the National Alzheimer's Disease and Related Disorders Association

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Board. We have 126 chapters across the country and 800 support groups. They are invaluable to help families just get through the day-by-day experiences and know that there is somebody else out there who is dealing with the same thing that you are and has the same feelings, the guilt, frustration, anger.

We need the education and the family groups to make people aware of what is going on with this disease. The respite care as you know, and the daycare centers are really prime targets that we need. There is one daycare center that I know of—and I will tell you later—that has a wing for Alzheimer's people.

Mrs. **BIEDERMAN**. Pasco?

Mr. **WAXMAN**. Thank you very much, Ms. Lester.

Let me say that if an award is to be given out it should be given out to the people in this area for having sent to Congress a man who has such deep caring and compassion and wants to do something for Alzheimer's people in this area.

Now, at the request of Mr. Bilirakis, I do not know how you quite handle this sort of thing. We usually have witnesses and know who they are going to be. But Mr. Bilirakis said that there may be people here who would like to come forward and say something and add it to the record so it will be shared by the Members of Congress.

If you do have something you would wish to say, I am going to turn over to Mr. Bilirakis the chairing of this part because I am not familiar with how you do this sort of thing.

Mr. **BILIRAKIS**. Thank you, Mr. Chairman.

Mr. **WAXMAN**. That is the democratic way.

Mr. **BILIRAKIS** [presiding]. It is something that I would like to do if we can. We cannot always manage to get it in. The chairman and his staff, Ruth Katz, will have to leave in a short while. They have a 2 p.m. flight to catch.

I would ask, in the interest of fairness, that the remarks be kept to a bare minimum. I know we have to get up in Congress and quite often say what we have to say in 1 minute's time. If we could maybe limit you to a couple of minutes I would appreciate it.

That is not intended just for you, Colonel, but of course anybody that would have any comments to make.

Go ahead sir; Col. Pat Imperato.

STATEMENT OF COL. PAT IMPERATO

Colonel **IMPERATO**. Mr. Chairman, Mr. Bilirakis, and the general public, I have lived in Florida for 35 years and in 34 of them I chaired 14 retiree organizations. If you want some testimony, you come to my meetings. The old have been through it. They know the answers. They do not go to any other source but each other.

In this process I became familiar with a health service agency of which I was a member for 3 years. We reviewed a lot of requests for aid. My background, I suppose, culls from having 15 members of my family with the same name as MDs and surgeons, one of them past superintendent of the Board of Health, New York City, one a medical clinical observer for the Federal Government.

I include 3 years myself in a health service agency, wherein, one day we received a letter from a retiree group that I had chaired 16 years ago requesting a survey to see if there was room for study and research in the field of chiropractor nutritionists.

Well, 50 percent HEW funds went toward this research and, believe it or not, up to one-third of Pinellas County goes to chiropractor nutritionists and it is in that field that I am addressing this group. I have here——

Mr. **Waxman**. Excuse me for 1 minute. Let me suggest this. We are going to keep the record open so if you want to have a prepared statement, however long it was going to be, we will put it all in the record. I do not know how many people here would like to be able to comment because I might be able to divide the time so that we do not spend all the time with the first person and then not have a chance for others.

I see one, two, three, four, five. Well, five people and if you each take 5 minutes, it adds up to 25 minutes. I know I am not going to be able to be here that long.

Mr. **Bilirakis**. I would very much like to have Chairman Waxman, because this is the committee that covers all medical matters, Medicare, Medicaid, you name it, medical research and that sort of thing, indeed, I think it is very critical that Mr. Waxman have the benefit of the grassroots views here. So, again, if we can limit these comments to a couple of minutes.

Mr. **Waxman**. Let me suggest this. We will set a timer for 3 minutes on each and then when the timer goes you will have to stop. If you want to add to the record you will be able to do it and then we will have additional thoughts which we will be able to review when they are in writing.

I am not going to be able to be here for everyone. And I apologize to those that I will not be able to hear directly, but I will have a chance to review the statements that will be in the transcript or your oral comments or any written points you want to make.

Why do we not start with you for 3 minutes and then we will have everybody up for 3 minutes.

Colonel **Imperato**. Thank you. The first thing I want to do, before I forget it, is to recommend—and I advise the Congress to listen—that we put nutrition in every medical college in this Nation, that we teach nutrition in all our public schools, that we have consumers on all boards of directors of all tax-supported hospitals.

I know it by heart. We should let loose in our institutions, especially the tax-supported institutions, chiropractor nutritionists. I will guarantee that the basis of these observations are predicated on probably 40 years of the research into health care costs. We are concerned with a lot of money here.

I will make another statement that you are not aware of. I am currently president of the State Council of Condo Associations. I have already geared up, cranked up the machines, that we will support the Congress' efforts to provide funds for these unfortunate people.

We have a slight provision. We would like a period of time in which the Congress can honestly evaluate the worth, if any, of these nutritional documents in our health care system and divert some of that money, even if it were in a trial period of time, in order to prove my contention, that these people have had literally hundreds of thousands of people out of our hospitals.

It is a new field, supposedly a new kid on the block, but you are talking to a person who understands nutrition because three of my brothers and myself have passed 50 years, married to the same woman, and that is two of us at a time because we had beans, potatoes and fruit and clean air.

Mr. **Waxman**. Thank you very much. We appreciate your testimony.

Mr. **Bilirakis**. Thank you, Pat.

[The statement of Colonel Imperato follows:]

Tureso   Office of Program - 1-27-86

PAT IMPERATO- LAND

[illegible]   [illegible]

[illegible]

Credentials: Served three years advisory council health service agency, [illegible] yrs. head of various retiree assn's, an important source of health care info, fifteen members of family, some here, M.D.'s, nurses, etc..etc..one, past Supt. Bd.of Health, N.Y.C. one, organizer of federal medical clinics nationally, one [illegible].

My concern today is the constant referral to medical sources for answers to our long term illnesses. In view of the dismal record compiled by this segment of our society, it follows we must go elsewhere for help, and I submit that we now go to the emerging chiropractor-nutritionist team that is producing [illegible] in the field of preventative medicine, especially that this profession has in hand cases of long term illnesses that have shown progress, as against the archaic methods still pursued by the medical doctor, producing a good standard of living for this slice of our civilization, and very little else. [illegible] a fast approaching bankruptcy on a national level.

Since 1970, chiropractic colleges have increased from two to eighteen, with 2000 graduates annually. We have 25,000 in practice, with almost 25 million patients. Fresno, Cal., Florida revealed considerable savings in accident cases, when the attending physician was a chiropractor, instead of a medical doctor. It was a factor in the decision of the Pinellas Co. School Board to place chiropractors on their medical panel. I made the presentation, personally. The study in Cal. and Fresno was conducted by medical doctors. The Florida study was instituted by my request to conduct a survey. 50% funded by HEW money, that revealed that up to 30% of [illegible] going to chiropractors for treatment of their ills.

We are now addressing "Alzheimers" disease. Our medical fraternity is totally in the dark as to a cure, a common conclusion for most illnesses. There is no progress is admitted and we are now addressing possible federal funding to help these unfortunate people. I ask my Congress to consider placing some of that money in an experiment whereby the chiropractor-nutritionist team treats all long term patients, and over a period of time compare the records of the medical doctor team against the new kid on the block. My research in the emerging chiropractor-nutritionist [illegible] shows considerable evidence that we should definitely go this new route, and since we have gone nowhere the old way, it follows; and I advise the Congress not to refer to any [illegible] agency to pass on my recommendations, as all those groups consist of medical doctors. Remember the "Fox in the hen house". Check the files in this area. And there exists locally two M.D.'s who have turned to heavy research in the field of nutrition, making gains treating long term illness, very happy to provide records showing these gains, namely, Ray [illegible], St. Petersburg, and [illegible] M.D., in Largo. There are others, but these two I have checked. I have a wealth of material available if needed, to further my position on how to best treat the long term patient, culled from medical journals, AMA records, etc. My unusual use of words are prompted by too many years observance of the [illegible] in our society, and I have to come across differently in order to make a point. I recommend the following to my Congress; Include nutrition in all medical colleges, place nutrition in the school rooms, place consumers on hospital directors of all non-profit hospitals, change food intake in hospitals to true nutritional [illegible], allow chiropractor-nutritionist teams in all tax supported institutions, and try a two year trial period by [illegible] all doctors, all levels, except [illegible] [illegible]. I have a million [illegible] used to say, but I must yield to others.

Thank you,
Pat Imperato, speaking for the
Fla. Council of Senior Citizen's [illegible]

P. Imperato

Clearwater "Sun"
Sunday, December 29, 1985
Comm

Alternative approaches to health care proposed

Letters to the Editor

Editor:

I would like to strike a blow for an emerging army of people in the health care business, also known as "alternate approaches" to good health care.

Years ago Congress decreed that more emphasis had to be placed on alternate approaches to healing people, the intent being to try anything that would help people in poor health, and at the same time lower health care costs. The old medical doctor approach is bankrupting this nation with the hordes of walk-in clinics feeding off, and in many cases, stealing the Medicare dollar, so easy to collect from the retiree flock of sheep dutifully lining up for shots, drugs, etc., 50 percent not needed and 50 percent more harmful than beneficial.

In 1978 I served three years on a regional health advisory board where we saved up to $28 million of construction money, denying doctors and sundry "promoters" the permits to build more hospitals (due to the fact we had too many empty beds already, a fact they were well aware of). In the process of studying means of cutting down health care costs, I came across a survey made in the 1960s down in Miami (First Research of Miami) that revealed very large savings in treating accident and sprain victims by chiropractic-nutritionists.

A letter from the South Pinellas Senior Citizen Club sparked research, 50 percent funded by HEW, that revealed up to 35 percent of Pinellas preferring chiropractic-nutritionist treatment. This was thrown into the hopper of health care studies and plans for the region, and to this day this alternate care has been shelved. Obviously the end result of all studies reaches the top echelon who decide the health care issues — and guess who composes 98 percent of that body? Medical doctors. Like putting the fox in the hen house for "protection"?

Further, every year, every malady known, M.S., diabetes, cancer, heart disease, Alzheimer's, etc., is thrown out at the public through golf tournaments, hospital clambakes, tennis tournaments, in an effort to raise funds to lick these diseases. The medical fraternity admits to ignorance in these maladies. So we give billions — to date — still no cures, so doesn't it make sense we turn to any alternate means of even partial victories?

We, the suffering public, have been hamstrung by the stranglehold the medical community has over any "upstart" trying to enter the sacred portals of disease control — and victories have been won. Lots of people are seeing results of the ever-increasing ranks of chiropractic-nutritionists producing results, real results, and now the time has come when our Congress must break the shackles that hold them to listening to only the medical doctor lobbies, including the powerful AMA, in matters of health care.

You would think by now Congress would welcome any approach that will blunt the billion dollar cost to taxpayers.

There is hope for many of you out there, but communication is lacking. Good, sometimes startling turnaround for suffering humanity is a reality. I fervently hope those who see this, call their congressman and begin to ask questions. Anything less I consider criminal.

PAT IMPERATO
Palm Harbor

Mr. Bilirakis. Who is next? This lady right here.

STATEMENT OF LINDA BARNABY

Ms. Barnaby. Chairman, I am Linda Barnaby. I am a native of Florida. My husband has had Alzheimer's disease since 1980 and the doctors told me it was probably 3 or 4 years before that and he was 54 years old. I have been to Dr. Pfeiffer. I have been to Bay Pines. I have been to everyone. I just got a letter Saturday from the President of the United States.

Why I asked about Bay Pines was, I am not asking for myself. I work. I am 63 years old. I have been 25 years with my company. I have an 87-year-old mother. I have a 34-year-old son who is committed, tried to commit suicide since 10 years old. So you think you have a problem.

Well, I went to Bay Pines and they told me I make too much. I wrote the President and I said——

Mr. Bilirakis. You went to Bay Pines for admission of your husband?

Ms. Barnaby. My husband—to get some kind of care. I do not have the money to go to a private doctor. My insurance will not take care of all this becasuse he has Alzheimer's. Alzheimer's, to me, is the same as cancer. It is a disease and Medicare had better learn that.

What I went there for and I asked the President—I am not asking for myself. My husband served in the South Pacific for 4½ years. I was not even married to him at that time. Why are they considering my salary?

When my husband was diagnosed as having Alzheimer's, we had just signed a home on the 13th of March for a mortgage, $56,000. On the 23d of March he was declared 100-percent disability. CAT scan, everything that went with it, my insurance paid for that and that is it. For 6 years.

I am left with a mortgage, with an 87 year old mother, a son. At 63 I am still working. I do have him in a daycare center. Thank God for that. He goes to school every morning. He thinks he is going to school because the bus picks him up.

But this man cannot bathe himself. He can sit there and feed himself. But if I told him to change his clothes, he would look at me or walk out the door. This man does not know what to do. I have to bathe him. I have to put the toothpaste on his toothbrush. I have to shave him.

Tell me that is not 24-hour day care.

Mr. Waxman. You are caught in a squeeze. You are not poor enough to get coverage. They will not cover you and you are working.

Ms. Barnaby. Right.

Mr. Waxman. Is your husband a veteran? I know you said——

Ms. Barnaby. Yes; 4½ years. Thank God for Dr. Goldberg. He is the only one that has been very kind to me. I did get in and talk to him. But they still do not have any care for me. I even offered to give my husband's brain as research to Bay Pines if I could get—if I know that it comes down where I have got to put him into a facility I cannot pay for a nursing home. I have got to finish paying for that home, take care of mother——

Mr. Bilirakis. Well, Mrs. Barnaby, the quality of the person shows up and Mr. Mackall is still here from Bay Pines. He did not just give his testimony and leave.

Mack, I do not know whether you have anything to add as far as this is concerned or will you be willing to talk to Mrs. Barnaby if she just gives up the mike at this point?

Will you please go over and talk to Mr. Mackall. He is with Bay Pines.

Ms. Barnaby. Saturday, I got the book for the Vietnam veterans to get all the rules and regulations of what you have to do. The President sent me a letter saying go to someone else for Bay Pines and they would represent me. But they are going to tell me right now, I make too much.

Mr. Bilirakis. That should not matter, should it?

Mr. Waxman. Well, what you are saying to us is an example of why we are here. The problems are that the people just are not covered.

People talk about the Federal Government's taking care of everybody, that they are great to them and all that—but the reality is that lots of people are caught in the middle. We provide sometimes for the very poorest and we require people to impoverish themselves before we will help.

Ms. Barnaby. I would be on welfare if I quit work.

Mr. Waxman. Yes. Thank you.

Ms. Barnaby. But I have also dealt with Dr. Pfeiffer and because my husband was too young they would not take him into the research program because the Government says you have to be 65 years and older. So, I do not know where to turn.

Mr. Waxman. Thank you very much for your testimony.

Mr. Bilirakis. Will you please step over and talk to Mr. Mackall, Ms. Barnaby. Thank you for bringing this to our attention.

Mr. Waxman. Yes; sir.

STATEMENT OF JOE KUTNER

Mr. Kutner. My name is Joe Kutner and my wife has Alzheimer's disease. As president of the Alzheimer's Disease Support Group of West Pasco, I testified last year at a similar hearing. I hope that my testimony and the testimony of others at that hearing laid a good foundation on which this testimony presented at this hearing can build to finally bring about a positive response from Congress to the critical needs of the Alzheimer's disease victim and the family.

Since September 1984, my wife is a resident of a nursing home at a monthly cost of approximately $1,800 and paid for with our retirement savings. Eventually, we will have to apply for Medicaid to help to keep her in a nursing home.

Let me pose a question. Suppose her income from Social Security was slightly higher than Medicaid qualifications? With no funds available, what do we do? Think about the consequences. It is a problem faced by many. We need an answer now. Thank you.

Mr. Bilirakis. Thank you, Joe.

STATEMENT BY PETER REUTER

Mr. REUTER. I appreciate this opportunity to speak today, Representatives Waxman and Bilirakis. I gave Mr. Bilirakis a written form that I would like to have included, including the extra articles. I think they are very beneficial and should be in the record.

Mr. WAXMAN. Without objection not only your statement but those additional articles will be in the record.

Mr. REUTER. Thank you. I come in the same line that Pat Imperato came here, that in the holistic movement where we use nutrition as a therapy. I believe all Alzheimer's could be prevented, if the individual still has, and can be able to do his personal needs and has some memory of recent activities, he would be able to be reversed and, at a minimum, stabilized at that point.

But many of them would be able to become completely recovered with a good nutritional program. This knowledge is here. In these statements here is a wellness letter from the University of California, Berkeley. They say again that prevention is the point and we do not need a medical miracle. All we have got to do is use the information that is already available for our nutritional program.

A major problem is our researchers in the medical, agriculture and nutritionist field have not compared the food with animals or human beings in the raw state versus that same food in a cooked or processed state.

Mr. WAXMAN. I want to thank you very much. Mr. Bilirakis gave me a copy of your article and we are going to put all of this in the record. Thank you very much.

Mr. REUTER. Correction is the way you are going to reduce costs. You are never going to cut costs by letting these people degenerate. They can be stopped and maybe even reversed in many cases. But whether the cases that these people are talking about today— do not get me wrong—I am not going to reverse any of those people.

[Testimony resumes on p. 385.]

[The statement of Mr. Reuter follows:]

When YOU Prevent ILLNESS, YOU Promote WELLNESS !

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Peter Roerer, Director

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January 27, 1986

Rep. Henry A. Waxman, Chairman
House Energy & Commerce Subcommittee on Health & The Environment
St. Marks Chapel
Palm Harbor, Florida

Dear Rep. Waxman and Committee members:

On May 1984 in this chapel Dr. J. Neil Henderson, Ph.D. presented the testimony of Dr. Eric Pfeiffer, M.D. to the House Select Committee on Aging. The following paragraph is a quote from his testimony.

"Alzheimer's Disease is a devastating disorder. Its cause is not currently known and no truly effective treatment is yet available. It is a disease in which brain cells die prematurely and progressively, causing progressive memory decline and general intellectual deterioration. It is a very variable disease whose course can run from two to twenty years after symptoms are first recognized."

In the opinion of the Life Balancing Center (LBC) he is describing a degenerative disease that is caused by inadequate nutrients reaching the brain to maintain normal function of the brain. Provide adequate nutrients in the form of fresh ripe whole foods and brain function will be improved. Vested interests have prevented the research of fresh ripe whole foods as a nutritional therapy for Alzheimer's or any other disease! In fact medical, nutritional and agricultural experts tell us that the nutritional values of cooked food is similar to fresh. This statement is based on chemical analysis only. Animal and human tests are necessary to determine the nutritional benefits of fresh vs. cooked and processed foods.

The Center's Tenets are founded in experience, human reason and truth; faith in and the study of Life, Nature and Science

Nutritional Value of Egg Beaters Compared with "Farm Fresh Eggs" is the only University level research study comparing a fresh vs. the processed form of the same food I have been able to locate. (copy is attached.) The chemical analysis table indicates a slight edge to the eggbeaters because nutrients were added to make it a better product than farm fresh eggs. The pictures show the great difference in five weeks of development on breast milk from the mother rat fed eggbeaters vs. the breast milk of farm fresh eggs. This is scientific proof that food processing destroys a large percentage of the nutrients that are in fresh food.

The most widely utilized diet in the USA is composed of mostly cooked and processed foods and is the primary cause of the numerous degenerative diseases so prevelant in the USA today and begins with low birth weight, birth defects, and all other degenerative diseases afflicting humans at various ages.

We are created to live a long healthful life without disease! Our responsibility is to fulfill our biological needs of the 100 trillion cells in the human body.

The attached article, Study adds to mounting evidence that brain grows, develops on into old age, supports the LBC viewpoint, that brain function of Alzheimer patients can be improved when they fulfill the biological needs of their brain and body by living a healthful natural lifestyle. The LBC experience indicates that it is normal to expect the body to heal itself when its biological need are fulfilled!

This whole body (wholistic) health improvement program would benefit only the Alzheimer patients who still retain some recent memory capability, and can take care of their personal needs without assistance. At the minimum the loss of memory would be stabilized and many Alzheimer patients will improve their memory and brain function capabilities.

It is not common-sense, nor is it economically sound and it does not benefit the Alzheimer patients to only fund medical research projects for Alzheimer's disease, when physicians say, they do not know the cause and know of no cure for Alzheimer's disease. & especially when a few thousand wholistic health professionals around the country and world know that it is preventable and reversable within the above stated limitations.

Therefore the LBC requests that H.R. 67 be amended to include the following:

That three of the ten demonstration programs be designated to three NIH approved Alzheimer medical research centers to evaluate the therapeutic effect of three wholistic health care programs, such as:

a. The Nathan Pritikin program, P.O. Box 5335, Santa Barbara, CA 93108. (Pritikin Program article attached)

b. Dr. Kenneth H. Cooper, M.D., author Aerobics book, Major USAF Medical Corps, Dallas, Texas

c. Life Balancing Center - Healthful Natural Living Guidelines program.

Specific instructions from the legislature are necessary because the Secretary of HHS, departments of NIH and NIA will not approve grants to research wholistic health care programs.

To obstruct funding non-medical wholistic health care research is a discriminatory practice - does not provide equal protection under the law. Medicare presently does not provide payments for wholistic preventive or therapeutic programs. Why - when they are more effective than medical care and the cost is lower. Example - the LBC charge for 10 weekly group meetings is $200. and a thirty day live-in program is $4,000.

Prevention and recovery of early stage Alzheimer's disease will reduce the pain, suffering and cost to the families of Alzheimer patients. This should be the primary reason to support the suggested amendment to H.R. 67 presently before your committee. Thank you for considering the LBC request to amend H.R. 67.

Respectfully yours

[illegible], Director, Life Balancing Center

Additional support articles attached.

Nutritional Value of Egg Beaters® Compared With "Farm Fresh Eggs"

The Council of Foods and Nutrition,[1] in a statement entitled "Diet and Coronary Heart Disease," has recommended that "In 'risk categories' it is important to decrease substantially the intake of saturated fat and to lower cholesterol consumption." The food industry has attempted to provide high-quality protein food items and for this purpose a new product, "Egg Beaters," has been introduced as a cholesterol-free egg substitute. It contains according to the label statement on the carton "egg white, corn oil, nonfat dry milk, emulsifiers (vegetable lecithin, mono and diglycerides and propylene glycol monostearate), cellulose and xanthan gums, trisodium and triethyl citrate, artificial flavor, aluminum sulfate, iron phosphate, artificial color, thiamin, riboflavin and vitamin D." A comparison of the nutrients in 100 gm of Egg Beaters with the nutrients in 100 gm of "farm fresh eggs" (Table 1) indicates a list of nutrients which should be able to meet the growth requirements of weanling rats.[2]

METHODS

In order to test this hypothesis, three groups of six lactating female rats each (Sprague Dawley strain), approximately 200 gm in weight, and their 2- to 3-day-old pups (5.4 to 6.8 gm in weight) were transferred from commercial laboratory chow (Purina) to either Egg Beaters, shell eggs, or kept on commercial chow as controls. The females and their young were kept in individual wire cages which contained shredded paper towels for nesting material. The litters were reduced at birth to six pups each; the females were allowed access to water *ad libitum*. For the sake of convenience, 100 shell eggs at a time were cracked into a Hobart mixer, 125 gm of calcium acetate added, blended for two minutes and stored at -20 C until ready to thaw and feed. Six cartons of Egg Beaters were thawed, 25 gm of calcium acetate added and blended for two minutes in a Hobart mixer. Both mixtures were stored in a refrigerator, poured into 4-oz glass jars and fed daily *ad libitum*. The calcium acetate was added in order to more adequately meet the recommended nutritional requirement for calcium.

TABLE I

COMPARISON OF NUTRIENTS IN EGG BEATERS® OR SHELL EGGS WITH NUTRIENT REQUIREMENTS OF GROWING RATS

Nutrients	100 gm of Egg Beaters	100 gm of Egg	Requirement of Growing Rat, % Diet[a]
Protein	11 gm	12.8 gm	13.5 gm
Fat	12.5 gm	11.4 gm	5.5 gm
Calories	166.66	160	GE/day 76 for each rat (444 Kcal/100 gm)
Ca (mg)	81.6 mg	54 mg	500 mg
P (mg)	71 mg	204 mg	440 mg
Na (mg)	161 mg	122 mg	60 mg
K (mg)	213 mg	128 mg	200 mg
Iron (mg)	1.8 mg	2.2 mg	30.9 mg
Cholesterol (mg)	<1.6 mg	550 mg	—
Vitamin A (unit)	1,550	1,180	.67 mg (retinol/Kg)
Vitamin D (unit)	45	50	111.1 (I.U./Kg)
Thiamine (mg)	.15	.1 mg	.14 mg
Riboflavin (mg)	.45	.3 mg	.29 mg
Choline Chloride	*	582 mg	83.3 mg/100 gm
Ca Pantothenate	*	2.7 mg	.89 mg/100 gm
Vitamin B_6	*	.3 mg	.78 mg/100 gm
Vitamin B_{12}	*	.001 mg	.00056 mg/100 gm
Biotin	*	.04 mg	.1 mg/100 gm

* Not listed.

RESULTS

The pups from the mothers fed Egg Beaters averaged 31.6 gm, and those fed whole egg averaged 66.5 gm in weight at 3 weeks of age as compared to 70 gm for pups from those fed laboratory chow. Both the mothers and pups fed Egg Beaters

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continued

Editorial by: - Life Balancing Center (LBC)

Why is it that our laws and regulations do not require all refined and reconstituted foods to be tested in this simple-cheap manner to determine how well they support life? They should be tested in accordance to the cooking instructions on the package to get a true nutrition answer.

The LBC experience indicates raw food is easier to digest, absorb and is metabolized to a greater extent by the cells than cooked food.

Raw food has its greatest impact during the embyro and development stage of life. It benefits all ages, lessons pain and corrects to some degree the chemical imbalances of each cell. The degree of improvement, dramatic or minimal, depends on the biological strengths and weaknesses of individual cells and organs, coupled with the effort put forth to fulfill the needs of the biological processes maintaining life!

It is the legislators' responsibility to provide the funds to do raw vs. cooked food tests to provide the nutritional information, so each individual can make an intelligent decision as to the foods they want to eat.

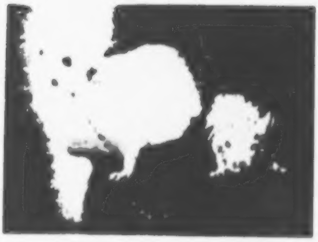

FIG. 1. Weanling rats fed shell eggs (*left*) or Egg Beaters (*right*).

developed diarrhea within one week; those fed whole egg did not develop diarrhea. The pups fed the two egg mixtures were weaned at 5 weeks of age. All of those fed Egg Beaters died within three to four weeks after weaning. The general appearance of the rats fed Egg Beaters indicated a gross deficiency in one or more nutritional factors as compared to those fed whole egg (Fig. 1). As the animals had a tendency to become coated with the Egg Beaters, the animals were washed gently with a mild detergent solution and dried with paper towels. The washing removed some of the hair as well as the Egg Beaters (Fig. 2).

COMMENT

Neither Egg Beaters or shell eggs serve as a single food source in the human diet. Furthermore, both Egg Beaters and shell eggs are subjected to heat treatment and not consumed in the raw state. In this study, the Egg Beaters and shell eggs were fed in the raw state to indicate whether Egg Beaters has the "nutrition of farm fresh eggs" and to preclude the use of Egg Beaters as a substitute for egg yolk in infant feeding by pediatricians who may consider supplementation with cholesterol-free substitutes early in life in order to prevent the development of atherosclerosis. The rat pups were weaned at 5 instead of the usual 3 weeks in order to provide the advantage of rat milk supplementation for them. However, it is evident that shell eggs, which contain the lipotropic-laden egg yolk, furnish one or more nutritional factors which are absent in Egg Beaters. These nutritional factors are no doubt present in the common food items which comprise the diet of human adults and could probably be added to the Egg Beaters formulation. However, these nutritional factors may not be present in adequate amounts for infants fed milk and Egg Beaters instead of egg yolk from a soft boiled egg. The Council statement[1] under point 3) should be considered: "Care be taken to assure that the dietary advice given does not compromise the intake of essential nutrients." This statement should also be considered in the quest of food items free of cholesterol in the diets of infants.

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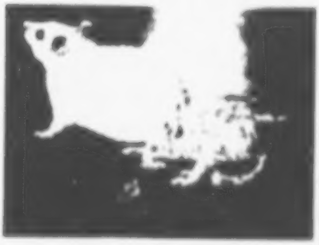

FIG. 2. Weanling rats fed shell eggs (*left*) or Egg Beaters (*right*). (Both animals were washed with mild detergent, rinsed and dried with paper towels before picture was taken.)

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ACKNOWLEDGMENT

We wish to acknowledge Dr. O. N. Breivik, Scientific Director, The Fleischmann Laboratories, Standard Brands, Incorporated, Betts Avenue, Stamford, Connecticut, for ten cases of Egg Beaters (Code Number 3106); Fort Wesley for his help in the feeding trials; Dr. F. V. Johnston for her helpful suggestions; and the late Miss Ethel Burnsides for funds she provided for support of The Burnsides Research Laboratory.

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Peter Reuter, Director

After reading Prof. Navidi's Egg report is there any wonder, why so many people are sick with degenerative diseases?

Join a LBC Healthful Natural Living Class to Look - Think and Feel Young Longer! When YOU Prevent Dis-Ease, You Promote Good Health!

Progress On The Pritikin Program

-Update & Report-

By MILES H. ROBINSON, M.D.

According to the American Heart Association "43.5 million Americans have one or more forms of heart or blood vessel disease." Over 10 million are afflicted with diabetes. In 1984, 202,000 people had bypass surgery. Last year $85.8 billion was spent on the treatment of these diseases.

What can be done to alleviate the human suffering associated with degenerative diseases and lower the nation's exorbitant health bill, now climbing past $400 billion? The goal of my presentation here today is to describe what we think is the most humanitarian and cost-efficient solution to this problem, which we have been using for the last nine years in our Longevity Centers.

In our program, along with moderate exercise, we reduce the fat in the diet from the average American intake of 40% of calories to 10%, and cholesterol intake from about 650 mg per day to 100 mg or less – in both cases about one-quarter as much as the average American eats.

These restrictions are not as extreme as they might seem. Dr. William Connor, at the University of Oregon and a panel member of the National Heart, Lung, Blood Institute, recommends that in stubborn cases of high blood cholesterol one should go to a 5-7% fat calorie diet if necessary.

In December 1984, the Heart Institute made recommendations which moved in our direction, but we think not nearly far enough. First, they announced that the blood cholesterol of most Americans is undesirably high as a result of the high intake of meat and dairy products. Second, every American over the age of two, whether well or sick from heart disease, should make a lifetime change of diet, reducing the intake of total fat from the current US average of 40% calories to 30% and cholesterol from 500 mg/day to not over 300 mg/day. Third, drugs should be used only as a last resort to lower blood cholesterol. Fourth, drugs should not be given unless accompanied by a strict low fat diet containing, if need be, as little as 20% of calories from fat. Finally, the goal for Americans should be their national average intake of 20% of calories from fat.

But what has this dietary recommendation accomplished in the past? The Heart Institute's 1982 $114 billion MRFIT government study used 30% fat and a limit of 300 mg of cholesterol per day, but there was no difference in risk of heart disease or death between the experimental group and the control group.

How does the Pritikin Program compare with this? In one month on our diet of 10% fat-calories, participants experience an average blood cholesterol drop of 25%. According to the Heart Institute's rule that for every 1% drop in blood cholesterol there is a 2% drop in heart disease risk, this translates to a 50% reduction in the risk of heart disease. Unlike drug therapy, no side effects are experienced on our program. Unlike a mild fat restriction from 40 to 30%, our restriction to 10% fat can also achieve a blood cholesterol level of 160 mg% which, according to the Framingham study statistics, almost eliminates the risk of cardiovascular disease.

Anybody can go on this diet without the supervision of a doctor, and we routinely prescribe it to everyone who comes to the Pritikin Longevity Center. Three to five years after leaving the Center we see an 80% compliance rate among those who have heart disease, diabetes, or hypertension. For healthy individuals, over 50% comply with the program.

Over 20,000 people in the past ten years have taken our 13-day or 26-day live in program of instruction in diet and exercise. We found that we can greatly decrease all symptoms of heart disease including angina. In a five-year follow-up study of patients with cardiovascular disease and a recommendation from their personal physician for bypass surgery, 80% of these patients avoided the operation – a saving potential of over $3 billion dollars alone. (Poster #1.) 85% of persons with hypertension achieve normal blood pressure and no longer need to take drugs. The Heart Institute is now recommending drug treatment for hypertension which could cost as much as $20 billion — at least half of which our regimen would save. (Poster #2) We take well over half of all adult-onset diabetics permanently off insulin and oral diabetic drugs.

$72 billion is spent on heart disease and $13.8 billion on diabetes every year. If 80% of the heart and diabetic population followed the Pritikin Program, which our compliance data for these individuals indicates is highly possible, $68 billion might be saved. If only 10% of them followed the Program, we would still see an annual saving of $8.6 billion.

The enormous cost of cancer can also be reduced by curbing dietary fat. A recent report from the National Academy of Sciences stated that the relationship between excess dietary fat and cancer is even more [illegible] established than the one between diet and heart disease.

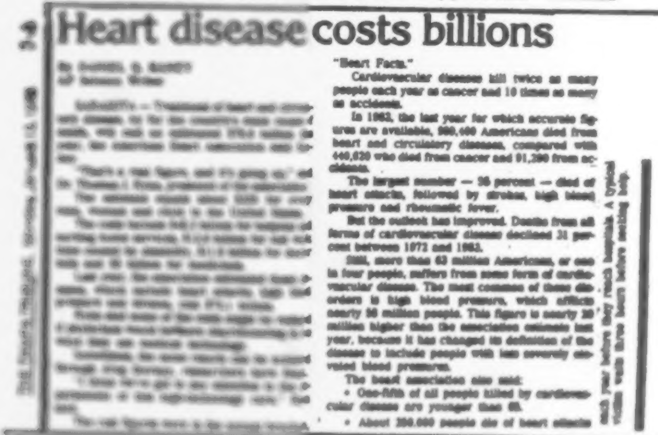
However, these tremendous savings will not be seen until people are fully educated in the prevention of degenerative diseases. We are pleased that many major institutions are modifying their nutrition recommendations and are moving closer to what we feel is the optimal program -- a 10% fat diet.

We feel this is no time for dilatory half-hearted measures. The present-day toll of cardiovascular disease and diabetes - to mention just these two - the misery and the cost of them - is just too great. Why climb slowly and gingerly down the ladder of dangerous dietary fat? Why ignore the ancient 10% fat diet still used all over the world by populations that do not have our epidemic of heart attacks? Would we recommend that a smoker simply cut back from 2 packs a day to 1? Of course not.

The evidence is very strong that the lower the intake of total fat, saturated fat, and cholesterol, the more favorable the effect on heart disease, and the greater the opportunity and likelihood for arteries slowly to open up again after being clogged by a lifetime of the over-rich diet which most Americans eat today.

We believe the public should not be left in the dark -- in complacent ignorance about the full extent of its safe and effective dietary options to prevent and treat the degenerative diseases of modern Western civilization.

This concludes my oral statement. Further details of our Program, and references to the scientific literature which support it, are contained in our written statement.



[illegible] 3-A

Heart disease costs billions

By [illegible]
AP Science Writer

[illegible]

"Heart Facts."

Cardiovascular diseases kill twice as many people each year as cancer and 10 times as many as accidents.

In 1982, the last year for which accurate figures are available, 980,400 Americans died from heart and circulatory diseases, compared with 440,620 who died from cancer and 91,280 from accidents.

The largest number — 56 percent — died of heart attacks, followed by strokes, high blood pressure and rheumatic fever.

But the outlook has improved. Deaths from all forms of cardiovascular disease declined 31 percent between 1972 and 1982.

Still, more than 63 million Americans, or one in four people, suffers from some form of cardiovascular disease. The most common of these disorders is high blood pressure, which afflicts nearly 58 million people. This figure is nearly 20 million higher than the association estimate last year, because it has changed its definition of the disease to include people with less severely elevated blood pressure.

The heart association also said:

- One-fifth of all people killed by cardiovascular disease are younger than 65.
- About 350,000 people die of heart attacks each year before they reach hospitals. A typical victim waits three hours before seeking help.

Life Balancing Center, Inc.

Peter [illegible], Director

[illegible] organization 1950 Sandra Drive, Clearwater, Fla. [illegible] Phone: [illegible]

10-A • THE TAMPA TRIBUNE, Thursday, August 1, 1985

Study adds to mounting evidence that brain grows, develops on into old age

By DANIEL GOLEMAN
New York Times

Studies show that environmental influences begin while the brain is forming in the fetus and are strong in infancy and early childhood.

NEW YORK — Evidence is building that development and growth of the brain go on into old age.

It was once thought that the brain was fixed by late childhood, according to innate genetic design.

As long ago as 1911, however, Santiago Ramon y Cajal, a pioneering neurobiologist, proposed that "cerebral exercise" could benefit the brain. But a scientific consensus that the brain continues to bloom if properly stimulated by an enriched environment was long in coming.

"Over the last decade, neuroscientists have become impressed by the degree to which the structure and chemistry of the brain is affected by experience," said Floyd Bloom, director of the division of neuroscience and endocrinology at the Scripps Clinic and Research Foundation in La Jolla, Calif. The new research seeks to provide a more detailed understanding of that phenomenon.

Investigations at several different laboratories have shown that environmental influences begin while the brain is forming in the fetus and are particularly strong in infancy and early childhood.

Among the most striking new evidence is a report published in a recent issue of Experimental Neurology showing that even in old age the cells of the cerebral cortex respond to an enriched environment by forging new connections to other cells. Marian Diamond, a professor of physiology and anatomy at the University of California at Berkeley, led the team of researchers who did the study.

In Diamond's study, rats 766 days old — the equivalent in human terms of roughly 75 years — were placed in an enriched environment and lived there until they reached the age of 904 days. For a rat, an impoverished environment is a bare wire cage a foot square with a solitary occupant; an enriched one is a cage a yard square where 12 rats share a variety of toys, such as mazes, ladders and wheels.

The elderly rats, after living in the stimulating environment, showed increased thickening of the cortex. This thickening, other research has shown, is a sign that the brain cells have increased in dimension and activity, and that the glial cells that support the brain cells have multiplied accordingly.

The brain cells also showed a lengthening of the tips of their dendrites, the branches that receive messages from other cells. This increase in the surface of the dendrites allows for more communication with other cells.

Previous studies have shown that enriched environments changed brain cells in a number of ways, these among them. While the specific effects differ from one region of the brain to another, in general the enriched environment has been generally seen to result in growth in the bodies of nerve cells, an increase in the amount of protein in those cells and an increase in the number or length of dendrites. In more fully developed dendritic spines, a part of the dendrite that receives chemical messages from other brain cells is believed to further growth.

Moreover, as in the new study, the thickness of the cortex was seen to increase, in part because of an increase in the numbers of glial cells needed to support the enlarged neurons. Diamond's studies on the older rats show that many, but not all, of these effects continue into old age.

These changes, in Diamond's view, mean that the cells have become more active, forming new connections to other brain cells. One sign of what the increased brain cell activity signifies for intellectual abilities is that the rats in the enriched environment became better at learning how to make their way through a maze. Indeed, Diamond and other researchers recently examined specimens from Einstein's brain. The tissue samples, from parts of the cortex presumed critical for mathematical skills, seemed to have unusually large numbers of glial cells.

What does all this mean for the aging brain? "There is much more neural flexibility in old age than we had imagined," said Roger Walsh, a psychiatrist at the University of California medical school at Irvine, who has done research similar to Diamond's. "The changes in brain cells have been found in every species investigated to date, including primates. They certainly should occur in humans as well.

"In my work," Walsh added, "I've found that an enriched environment in late life can largely compensate for brain cell deficiencies from earlier deprivations."

"We've been too negative in how we view the human brain," Diamond said in an interview. "Nerve cells can grow at any age in response to intellectual enrichment of all sorts: travel, crossword puzzles, anything that stimulates the brain with novelty and challenge."

Still, there seem to be limits to the degree to which the brain can respond to experience. Richard Lerner, in "On the Nature of Human Plasticity" (Cambridge University Press), notes, for example, that the impact of environmental enrichment on brain cells seems to diminish with age, although it continues into old age, an effect Diamond has noted in her research.

The effects of enriched environments on the brain are but part of a larger investigation of the impact of life's experiences on the brain, and the picture is not always positive.

"Brain plasticity can operate for better or for worse," said Jeannine Herron, a neuropsychologist at California Neuropsychology Services in San Rafael. Herron has organized a conference to be held later this month at which Diamond and other researchers will describe their findings.

Perhaps the most frequently cited example of how experience — or the lack of it — can have a negative effect on the the brain is the

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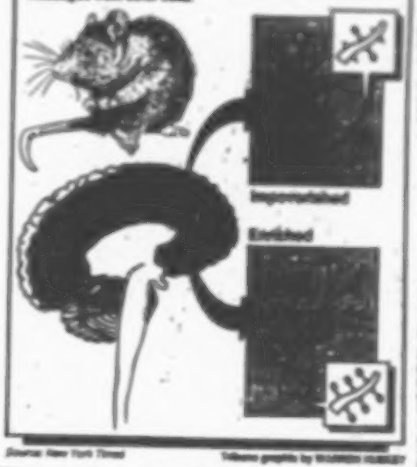
Brain growth in rich environment

[illegible]



Source: New York Times

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[illegible]

Brain tries to fight damage of Alzheimer's, study finds

[illegible]

LOS ANGELES — [illegible]

[illegible]

Exercise also helps in building mental 'muscles'

[illegible]

Medical Self-Care:

Sound Nutrition, Healthier Aging

Medical Self-Care

crease bone mass after age 35. In one study, elderly women who participated in a three-year exercise program showed a bone-mass gain of 2.9%, while a sedentary control group suffered a 3.3% loss.

Now's the Time to Change

Elders (and young people who want to age healthily) should continue to eat as few processed or unnecessarily prepared foods as possible. Simple techniques can be used to create low-salt, low-fat, nutrient-dense meals that are wonderfully tasty. Any food that you might ordinarily fry or sauté in oil (fat) is better for you if broiled, baked, or steamed, or if sautéed in liquid: water, vegetable or chicken broth, or water and herbs. Herb seasonings—such as garlic, tarragon, dill, oregano, and cilantro—make appetizing substitutes for salt. (As your salt consumption decreases, your craving for it will, too—in time, salt-free foods may taste bland.)

The same fresh fruits, vegetables, and leafy greens in your diet, the better. And it's a good idea—especially for women—to eat foods rich in calcium throughout life: skim and low-fat milk products, soy products, leafy greens, beans, nuts, seeds, and seafood. Calcium supplements are another possibility.

The point is, advancing age need not bring physical and mental deterioration. Sound nutrition and daily exercise can keep us looking and feeling younger even as we grow older. And there's no time like the present for making a change for the better.

EDITOR'S NOTE: Medical Self-Care, Dr. Tom Ferguson's bimonthly (six issues a year) journal, is available for $11.97 annually from Medical Self-Care, P.O. Box 717, Inverness, CA 94937. A sample issue costs $3.00. Dr. Ferguson's a coauthor, with David Sobel, M.D., of The People's Book of Medical Tests, available from the same address for $12.95 plus $1.25 postage (California residents please add 6% tax). ●

UNIVERSITY of CALIFORNIA, BERKELEY
WELLNESS LETTER February 1986
The newsletter of nutrition, fitness and stress management

The magic bullet is prevention

A major five-year study at the Carter Center at Emory University in Atlanta recently identified the 14 primary causes of illness and premature death (deaths before the age of 65) for which preventive action can be taken. The causes included infectious diseases, infant mortality, drug abuse, cardiovascular disease, and cancer. Together the 14 problems are responsible for 85% of all personal health-care costs and 80% of deaths in America. They also account for 90% of the "potential years of life" lost in America (the term "potential years of life" is defined as the difference between age at death and age 65), which adds up to a staggering 8.5 million years of life lost annually. *Approximately two thirds of these deaths under age 65 are potentially preventable.* The clear conclusion was that we can turn ourselves into a healthier nation by making more effective use of the knowledge we already possess. We are not dependent on medical breakthroughs to achieve an enormous improvement in our nation's health.

The study also identified modifiable risk factors having a major impact on each of the 14 health problems. The six risk factors most frequently cited were tobacco, alcohol, injuries, unintended pregnancy, lack of preventive services, and improper nutrition.

Tobacco was identified as the single leading cause of death—1,000 deaths in America each day, all of them preventable. (Tobacco causes more deaths through circulatory disease than through cancer, though many cancer deaths are also tobacco-related.) To combat the smoking epidemic, the study recommended measures to make nonsmoking the societal norm. It suggested, for example, that educators and the public explore the ethical dilemma posed by the continued production of tobacco for profit. The study also produced many innovative proposals for future policy: one suggestion was to compensate victims of tobacco-related diseases.

Alcohol, the second most important risk factor, is discussed in the Wrap-up of this and the next issue of the *Wellness Letter*. In subsequent issues we will continue to examine these general risk factors and how they can be reduced. ●

6A ST. PETERSBURG TIMES ● FRIDAY, JANUARY 17, 1986

Infant health decline in U.S. assailed

By CRISTINE RUSSELL
Washington Post

WASHINGTON — Two decades of progress in improving the health of poor and minority mothers and their babies has "ground to a virtual halt," according to the Children's Defense Fund.

The group said government statistics document not only a "marked slowdown" in the decline of overall infant mortality, but an "alarming" national increase in deaths among infants between one month and one year old.

In 1983, this death rate rose 3 percent nationwide. "Not since 1970 has there been a nationwide increase in the postneonatal mortality rate and not in 18 years has there been such a large one-year increase," the advocacy group said.

"This trend is disturbing," said the group's president, Marian Wright Edelman. She said deaths among babies over one month old are "usually a reflection of environmental conditions related to poverty, such as poor nutrition, inadequate housing and sanitary conditions and lack of basic health care, which are largely preventable."

"It's disturbing until we know more about it," said Dr. Joel Kleinman of the government's National Center for Health Statistics. But, he cautioned, "So far we haven't been able to come up with a clear explanation of what's going on" or even whether there is a trend.

"I think it's shameful that a black infant in Chicago, Cleveland, or Detroit was more likely to die in the first year of life than an infant born in Costa Rica," said Edelman.

For additional info or a presentation for your employees call or write

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The Center's Tenets are founded in experience, human reason and truth, faith in god the study of Life, Nature and Science.

Elderly malnutrition Poor eating habits may contribute to more illness than previously thought

By ERIK ECKHOLM
New York Times

NEW YORK — [illegible]

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Health

of his malnourished patients.' The [illegible] improvement "is not in the levels seen in young people, but it is significant," he said. "We believe it can reduce their burden of illness and improve their quality of life." In support of his claim that malnutrition accounts for a much greater share of the decline in the immune systems of the elderly than is generally recognized, Chandra noted that not every older person suffers such impairment. "Some 80- or 90-year-olds have immune systems almost as good as those of a 40-year-old," Chandra said. He said [illegible] in Europe provide evidence backing his position.

Studies directed by Dr. David A. Lipschitz of the John L. McClellan Memorial Veterans Hospital in Little Rock, Ark., also have shown that immune responses in elderly patients suffering protein-calorie malnutrition can often be improved by nutritional therapy. In an interview, however, Lipschitz emphasized that strong evidence also indicates that aging lowers the immune system significantly in any case.

Lipschitz said that correction of severe malnutrition can unquestionably improve a patient's disease resistance, but that in cases of milder deficiencies the immunological benefits of supplementary feeding were less certain. "The interrelationship between nutrition, aging and immunological decline is quite complex," he said, adding that it is also poorly understood.

Confounding all estimates of geriatric malnutrition is a lack of knowledge about the true dietary needs of the elderly. The federal government now provides the same recommended daily allowances, or RDA's, for various nutrients for everyone above the age of 51.

"It's clearly not the case that a 53-year-old and a 91-year-old have the same nutritional needs," said Blumberg. Defining new RDA's for the aged is one of the priorities at the Tufts center. According to Blumberg, existing recommendations are probably far too low in the case of calcium, a mineral found mainly in dairy products and the underconsumption of which encourages bone degeneration. He said the RDA's might be too low or too high for several other nutrients.

Many elderly people, experts say, fall into a spiral of undereating, illness, physical inactivity and depression.

"Most older patients are relatively malnourished," said Dr. William R. Hazzard, director of the Center on Aging at Johns Hopkins University. Whether or not undernourishment caused their disease, he said, "turning around the problem often requires nutritional intervention."

In interviews, several experts said that awareness of geriatric malnutrition is increasing rapidly in the medical community and that hospitals with special geriatric units usually spot and treat the condition. But they said that less specialized hospitals and physicians often overlook the nutritional roots of illnesses.

"Elderly patients are admitted to the hospital with dehydration, infections or mental confusion," Lipschitz said. "These conditions are diagnosed and treated, but the prime problem, mainly that the person is consuming inadequate calories or protein, may be missed."

High-protein items like meats are expensive and often hard to chew, noted Ronni Chernoff, a nutritionist and a colleague of Lipschitz at the veterans hospital in Little Rock. And few of the elderly consume enough dairy products to provide sufficient protein.

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D ST PETERSBURG TIMES ■ THURSDAY, DECEMBER 6, 1979

Bad nutrition masquerades as 'old age'

By JANE E. BRODY
© New York Times

NEW YORK — Mrs. W., a 75-year-old widow, has been eating haphazardly since her husband died a year ago. Practically every day for half a century, she had eaten breakfast and dinner with him, well-balanced meals that she prepared on weekdays, he on weekends.

Now, somewhat depressed and chronically lonely, she had little interest in cooking and even less in eating. Her appetite meager, she ate mainly because she knew she should. Coffee, toast and jelly sufficed for breakfast, canned soup and Saltines for lunch, and "a can of something," hot dogs or a TV dinner for supper with instant pudding or Jell-O for dessert.

Although she had been active, healthy and slightly plump all her adult life, now her weight and her energy level were well below normal and she had begun to have severe headaches and occasional dizzy spells.

AT HER DAUGHTER'S insistence, Mrs. W. finally paid a visit to the doctor. The diagnosis surprised her:

"Your headaches and dizziness are undoubtedly caused by your blood pressure, which is too high, probably because of the stress of being a widow but also because those prepared foods you've been living on are loaded with sodium. Your weight is down because you simply aren't eating enough. Anemia is contributing to your poor appetite and your lack of energy. You're eating too few fresh foods and too little protein. You're probably deficient in several important vitamins and minerals, in addition to the iron deficiency that's causing your anemia."

There are millions of Mrs. W.'s and their male counterparts throughout our affluent land — elderly people who, for a variety of reasons, compromise their health and ability to function by eating poorly. Not all are widows or widowers having no one but themselves to cook for and eat with. And not all are poor. Nutritional deficiencies are also commonly found among relatively affluent old people. Some are semi-invalids who have difficulty shopping for and preparing nutritious food. Some who live in urban centers are afraid to go out and risk becoming victims of street crimes. Some are depressed, which robs them of an appetite and interest in taking care of themselves.

SOME HAVE no teeth or poorly fitting dentures and can't chew anything but soft foods, many of which are high in refined carbohydrates and low in essential nutrients. Some have medical problems that restrict the kinds of foods they can eat, often eliminating those that are most appealing.

Many live on a fixed income and must spend increasingly large proportions of it to keep a roof over their heads, necessitating reduced expenditures on food, the only flexible part of their budget.

Nutrition

from 1-D

Families are often unaware of the nutritional plight of elderly persons who live alone. They tend to accept the physical and mental decline of their older relatives as the inevitable consequences of age, not realizing that much of the deterioration is potentially avoidable.

Those who live to a "ripe old age" need not be doomed to spend the last portion of it shriveled, confused and decrepit. Good nutrition is certainly not a fountain of youth, but it can go a long way toward prolonging useful life and helping to preserve youthful structures beneath an aging facade. And megadoses of vitamins and minerals are not necessary to achieve this.

ALTHOUGH RELATIVELY little is known about the precise nutritional requirements of the elderly, what is known is that a significant percentage of older Americans — perhaps a third or more — are shortchanged on one or more essential nutrients, including protein, calcium, iron, several B vitamins, vitamins C and D, fiber and total calories. The insidious results of these deficiences may include reversible symptoms of senility, chronic constipation, fragile bones, "shrinkage" of the body, and a loss of energy and zest for life.

In addition, the foods the elderly do eat may increase their likelihood of developing diabetes, cancer, bone fractures, high blood pressure, heart disease and stroke.

As a person ages, body structure changes. The proportion of the body that is lean tissue (muscle and bone) decreases and the proportion that is fat increases. Since fat requires less energy than lean tissue to support itself and since most people become less active in their later years, caloric needs decline five to 10 percent each decade after 20 even if body weight never changes.

IN OTHER WORDS, unless you eat considerably less at 60 than you did at 20, you'll gain weight. That's what middle-age spread is all about. Extended to the later years, this overweight can add stress to a weakened bone structure and increase the risk of diabetes, high blood pressure and heart disease.

At the same time that you need fewer calories, however, your requirements for basic nutrients are thought not to diminish. Thus, you have to pack more nutrients into less food. As you age, there's less and less room in your diet for "junk" foods high in calories and low in nutrients.

To meet your nutritional requirements, you should reduce your intake of sweets, refined starches and fats, concentrating instead on foods rich in protein, vitamins and minerals such as lean meat, fish and poultry, high-protein plant foods (dried beans, dried peas, nuts and seeds), fruits and vegetables, whole-grain breads and cereals and dairy products.

POOR TEETH or dentures, digestive problems and longstanding food prejudices keep many old people away from foods high in fiber. Yet fibrous foods — including fresh fruits and vegetables, whole grains and dried beans — can help counter several common problems among the elderly, especially constipation and diverticular disease, and may help to prevent colon cancer, diabetes and the formation of gallstones.

Many older people compound their nutritional problems by taking mineral oil and other laxatives that cause their bodies to lose the fat-soluble vitamins A, D, E and K.

The strength of your bones, including possibly the bones that keep your teeth from falling out, depends largely on an equal or better ratio of calcium to phosphorus in your diet. Excess phosphorus tends to enhance the loss of bone as you get older. Yet the typical American diet contains at least three times more phosphorus than calcium.

MAIN SOURCES of phosphorus, all being consumed in ever-increasing amounts, include meat, soft drinks, cheese, snack foods like crackers and chips, and many processed foods that use phosphorus-containing food additives (phosphates). Processed cheeses contain more phosphorus than calcium.

Regular cheese and milk, the major dietary sources of calcium, contain nearly as much phosphorus as calcium; besides, milk consumption has been steadily declining for years. Other foods rich in calcium include sardines and canned salmon (with the bones), yogurt, cottage cheese, sesame seeds, molasses, seaweed, collard greens and spinach.

Too much fat and cholesterol in your diet can add to your risk of heart disease and stroke. Many people erroneously think that after a lifetime of eating a fatty diet, it's too late to change. A number of studies suggest otherwise.

Given half a chance by your diet, your arteries have the potential ability to cleanse themselves naturally of some of the deposits they've accumulated through the years.

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Mr. Waxman. Thank you very much.

Now for our last person.

STATEMENT OF KEN RHODES

Mr. Rhodes. Thank you very much. I am Ken Rhodes, a native of Florida and a resident taxpayer of Palm Harbor. I want to speak for the people who have had a serious reduction in their quality of life because of memory problems, but do not have Alzheimer's. I have a couple in my family and I will tell you that it is terrible because there is no place to turn.

Dr. Pfeiffer, I believe, has gone but I have been in touch with the Suncoast Gerontology Center, I have been to Shands Hospital, University of Florida, write to the National Council on Aging, write the American Association of Retired People. Mr. Waxman, you several times have mentioned a center of knowledge, but these places send you back an inch and a half of paper and you can write to them.

All these articles that are copied out of journals and so forth, there is no positive action. Meanwhile, there is no place—you cannot go to the Suncoast Gerontology Center and get an answer.

You can go through their program. They have very few doctors. They concentrate on the psychology and you can go through their program, pay their fee, get their test and when you get through they will tell you the results of their tests.

They will not tell you what one can do. Is it possible to improve your quality of life? Can you do this? Can you do that? Can you do the other?

What we are faced with is something not nearly as spectacular as Alzheimer's where you need this warehousing for long-term care. You have these people where you are faced with 5 years, 10 years down the road of saying, oh—if only I had—think of all the good years they could have had.

But now they do not function. It could be depression. It could be diet. It could be the 30 pills that various doctors have given them to take every day. But nowhere can one go and find—come take our test, come to this center, we will put you through it and we will tell you what you may do to improve the situation or at the limits of knowledge today, there is nothing you can do. See, there just is no way.

Mr. Waxman. So, you do not know whether it is the limits of knowledge or whether somebody has this information and you just do not know how to get access to it?

Mr. Rhodes. Exactly right. Several of the people that have testified today, that when their loved ones actually wound up having Alzheimer's, but they told you of the long, tedious year—way over a year—you go to this doctor, you go to that doctor

There is no way to start out intelligently and say, I am going to find out the answer. What is the way to go? There must be 100 of these people for every one with Alzheimer's. If a center of knowledge and I mean truly, you could identify someone, some group in the State of Florida where we could go, doctors could be certified, doctor groups could be certified.

Mr. **Waxman**. One of the things we have tried to do is—we have jurisdiction over the National Institutes of Health—we have tried to push them or some of the people there who do research to get more application of that work so it would be beneficial to people right away.

Second, where there is prevention, we want them to let people know how to prevent the problems if we can. This is another problem you are raising that I think we will need to discuss with them because people are hungry for information.

When you have a family member and you are trying to find out what is happening, you ought to be able at least to get—if not an answer from your local people who may not know the state of the art in research—at least they should be able to contact the National Institutes of Health and find out what the state of the art is, what the latest knowledge is so that it can be available. Thank you very much.

Mr. **Rhodes**. It will not help for them to send back all the articles that have been written on the subject.

Mr. **Waxman**. That may be all they have. Thank you all very much. This has been an excellent hearing. I thought we had finished but apparently—we are going to have to conclude—a short one and then we are going to have to conclude.

STATEMENT BY FRED RITZ

Mr. **Ritz**. Let me get this in here, an excerpt from the St. Petersburg Times of Saturday, January 25. My name is Fred Ritz, like Ritz crackers. I belong to the West Pasco Support Group. My wife has Alzheimer's.

The head of an insurance industry trade association said Friday that his group will oppose any Reagan administration effort to expand Medicare to cover catastrophic illnesses. He called it a direct slap in the face of the American private insurance industry.

Jack O'Day, head of the Insurance Economic Society, said in a news conference that the plan drafted by Health and Human Services Secretary Otis R. Bowen is curiously contradictory to the administration's own free market philosophy.

By various estimates, between 65 percent and 75 percent of Medicare recipients now buy so-called Medigap insurance policies to cover hospital expenses not covered by Medicare. But Secretary Bowen has argued that Medicare beneficiaries buying Medigap policies get relatively little coverage for a substantial premium. Thank you, sir.

Mr. **Bilirakis**. Thank you.

[The article referred to by Mr. Ritz follows:]

[From the St. Petersburg Times, Jan. 25, 1986]

UPDATE—INSURANCE OFFICIAL OPPOSES CATASTROPHIC MEDICARE COVERAGE

The head of an insurance industry trade association said Friday that his group will oppose any Reagan administration effort to expand Medicare to cover catastrophic illness. He called it "a direct slap in the face to America's private insurance industry." Jack O'Day, head of the Insurance Economics Society, said at a news conference that the plan drafted by Health and Human Services Secretary Otis R. Bowen "is curiously contradictory to the administration's own free-market philosophy." By various estimates, between 65 percent and 75 percent of Medicare recipients now buy so-called Medigap insurance policies to cover hospital expenses not covered by Medicare. But Bowen has argued that Medicare beneficiaries buying Medigap policies get relatively little coverage for a substantial premium.

Mr. **Waxman**. Let me make one comment to you in conclusion. When we get that proposal from the President of the United States—and I am anxiously looking forward to it—we are going to have hearings.

I am going to try to move forward on catastrophic care and we will be glad to hear from the insurance industry and others. That is our job. We will see what we can do about getting legislation. Thank you all very much for attending.

[Whereupon, at 12:35 p.m., the subcommittee was adjourned.]

[The following statement was submitted for the record:]

Testimony

MRS. JOHN ASHCROFT

"The Comprehensive Alzheimer's Assistance, Research
and Education Act of 1985"

Submitted for the
Health Subcommittee of the U.S. House of Representatives
Committee on Energy and Commerce

THANK YOU, CHAIRMAN WAXMAN, FOR THE OPPORTUNITY TO TESTIFY IN SUPPORT OF H.R. 2280, "THE COMPREHENSIVE ALZHEIMER'S ASSISTANCE, RESEARCH AND EDUCATION ACT OF 1985." IT IS AN HONOR FOR ME TO LEND MY SUPPORT TO THIS IMPORTANT INITIATIVE SPONSORED BY, AMONG OTHER CONCERNED MEMBERS OF CONGRESS, CONGRESSMEN CLAY AND SKELTON FROM MISSOURI.

AS FIRST LADY OF MISSOURI, I HAVE DECIDED TO LAUNCH A SERIES OF EFFORTS TO HELP ENHANCE THE QUALITY OF LIFE FOR OLDER MISSOURIANS, INCREASE PUBLIC AWARENESS OF THEIR PROBLEMS, AND IN PARTICULAR, PROMOTE A BETTER UNDERSTANDING OF THE EFFECTS OF ALZHEIMER'S DISEASE.

AS PART OF MY EFFORTS TO PROMOTE THE CAUSE OF THE ELDERLY IN OUR STATE, I HAVE AGREED TO SERVE AS THE STATEWIDE LIAISON TO THE ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION FOR MISSOURI. I AM CONVINCED THAT THE EMOTIONAL AND FINANCIAL BURDEN THAT ALZHEIMER'S DISEASE PLACES ON OUR AFFECTED CITIZENS, THEIR FAMILIES AND THE STATE OF MISSOURI MUST BE BROUGHT TO THE FOREFRONT IMMEDIATELY.

AS STATE LIAISON, I BELIEVE THIS LEGISLATION WOULD HAVE A SIGNIFICANT, POSITIVE IMPACT AT THE STATE AND LOCAL LEVELS. IT MAKES AVAILABLE THE RESOURCES NECESSARY TO IMPROVE THE

COORDINATION OF ALZHEIMER'S INITIATIVES WITHIN OUR STATE. IT ALSO PROMOTES POLICY CHANGES WHICH WOULD BENEFIT VICTIMS AND FAMILY MEMBERS OF ALZHEIMER'S DISEASE.

OVER TWO MILLION AMERICANS ARE AFFLICTED WITH THIS TERRIBLE DISEASE -- WHICH HAS BECOME THE FOURTH LEADING CAUSE OF DEATH AMONG THE ELDERLY. IN MISSOURI, ESTIMATES ARE THAT 61,980 OF OUR OLDER ADULTS ARE VICTIMS OF ALZHEIMER'S. I AM PERSONALLY FAMILIAR WITH THE PAIN AND SORROW CAUSED BY THIS DISEASE, AS IT CLAIMED MY FATHER'S LIFE IN 1985.

NOT ONLY IS ALZHEIMER'S PHYSICALLY AND EMOTIONALLY DRAINING TO VICTIMS AND CAREGIVERS, IT IS FINANCIALLY DEVASTATING. ESTIMATES ARE THAT 50% OF ALL NURSING HOME ADMISSIONS ARE DUE TO ALZHEIMER'S OR A RELATED DEMENTIA. THIS WOULD RESULT IN A COST TO THE STATE OF MISSOURI OF OVER $100,000,000 ANNUALLY IN MEDICAID PAYMENTS ALONE, IN ADDITION TO THE MILLIONS OF DOLLARS SPENT BY PRIVATE PAY AND MEDICARE PATIENTS. DESPITE GENERAL PUBLIC PERCEPTION, THIS DISEASE IS NOT A NORMAL CONSEQUENCE OF THE AGING PROCESS. IN MY ROLE AS LIAISON, I HOPE TO ENCOURAGE LOCAL AND STATEWIDE FUND RAISING PROGRAMS WHICH WILL ASSIST THE NATIONWIDE SEARCH FOR A CURE. UNTIL SUCH TIME THAT A CURE IS FOUND, I AM WORKING TO SUPPORT, EXPAND AND COORDINATE THE FAMILY SUPPORT GROUPS THAT ARE NECESSARY TO HELP EACH OF US DEAL WITH THIS DISEASE.

I AM ALSO COMMITTED TO ENSURING A CONSISTENT DIRECTION FOR ALZHEIMER'S EFFORTS IN MISSOURI. TOO OFTEN, A VARIETY OF ORGANIZATIONS ENDORSE AN ISSUE, AND -- ALTHOUGH DEDICATED TO THE PROBLEM AND ITS SOLUTION -- WORK IN DIVERSE DIRECTIONS. AS LIAISON, I HAVE FOCUSED MY ENERGIES ON THE COORDINATION OF FAMILY SUPPORT GROUPS. THIS CONCEPT IS EMBODIED IN H.R. 2280.

A STRONG SUPPORT GROUP NETWORK HAS THE ADDED BENEFIT OF PROVIDING A RURAL EMPHASIS. OUR RURAL ELDERLY ARE OFTEN

OVERLOOKED, LIVING ALONE WITH LIMITED CONTACT TO THEIR SURROUNDING COMMUNITIES. LOCAL SUPPORT GROUPS CAN BRIDGE THIS GAP, AND PROVIDE VALUABLE SERVICES TO ALL ALZHEIMER'S SUFFERERS.

STATISTICS SHOW THAT AT LEAST ONE PARENT WILL SUCCUMB TO ALZHEIMER'S IN ONE-THIRD OF ALL AMERICAN FAMILIES. IT IS IMPORTANT TO PROVIDE THE TRAINING AND MUTUAL UNDERSTANDING THAT WILL HELP THE FAMILY MEMBERS COPE WITH THIS TRAGIC SITUATION.

IT IS EQUALLY IMPORTANT FOR US TO EDUCATE THE PUBLIC ABOUT THE SYMPTOMS -- AND THE EVENTUAL RESULTS -- OF ALZHEIMER'S DISEASE. AS STATE LIAISON, I AM WORKING TO IMPLEMENT PROGRAMS WHICH WILL ASSIST IN THIS EDUCATIONAL EFFORT.

THROUGH THE MISSOURI DIVISION OF AGING, AN "INFORMATION BANK" HAS BEEN DEVELOPED WHICH PROVIDES UP-TO-DATE FILMS, PAMPHLETS AND BROCHURES ON ALZHEIMER'S TO CHURCH GROUPS, SCHOOLS, OR INTERESTED MISSOURIANS -- LIKE FAMILY SUPPORT GROUPS -- WHO NEED ADDITIONAL INFORMATION ABOUT THIS DISEASE. I ENDORSE THE DEVELOPMENT OF VOLUNTEER PROGRAMS TO EDUCATE PUBLIC SERVANTS -- LAW ENFORCEMENT OFFICIALS, FIREFIGHTERS, SOCIAL WORKERS -- ABOUT THE POTENTIAL FOR ALZHEIMER'S "WANDERERS" AND THE WAYS TO DEAL WITH THEM. AGAIN, A COORDINATED NETWORK IS NEEDED THROUGHOUT MISSOURI TO ENSURE THE SUCCESSFUL IMPLEMENTATION OF THESE PROGRAMS AND OTHERS.

TO THAT END, I MET IN NOVEMBER 1985 WITH REPRESENTATIVES FROM THE NATIONAL AND STATE CHAPTERS OF THE ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION (ADRDA) TO DISCUSS PLANS FOR THE FUTURE OF ALZHEIMER'S INITIATIVES IN MISSOURI. WE HOPE TO ESTABLISH AN ALZHEIMER'S "COALTION" -- COMPOSED OF ADRDA CHAPTER MEMBERS -- WHICH WILL COORDINATE THE STATE AND LOCAL FUND-RAISING EVENTS. WE ALSO PLAN TO USE THIS COALITION TO DISSEMINATE INFORMATION FROM THE UNIQUE PERSPECTIVE OF THOSE WHO HAVE EXPERIENCED THE TRAUMA OF ALZHEIMER'S. THIS INFORMATION WILL BE

FOCUSED ON MEDICAL RESEARCH, THE ROLE OF FAMILY MEMBERS AND THE NEED FOR SUPPORT GROUPS.

MISSOURI REPRESENTATIVES FRANCIS BRADY AND CAROLE ROPER PARK HAVE PROPOSED LEGISLATION TO THE MISSOURI GENERAL ASSEMBLY TO ESTABLISH A STATEWIDE ALZHEIMER'S TASK FORCE. THIS TASK FORCE WOULD REVIEW AND EVALUATE THE PROGRAMS SERVICING ALZHEIMER'S PATIENTS AND THEIR FAMILIES, WHILE PROVIDING GUIDANCE FOR A MORE COMPREHENSIVE AND EFFECTIVE METHOD OF SERVICE DELIVERY THROUGHOUT THE STATE. THIS CONCEPT IS A MAJOR COMPONENT OF THE PROPOSED "ALZHEIMER'S ACT OF 1985," AND OUR TASK FORCE WOULD BE CONSISTENT WITH THE APPROACH SUGGESTED AT THE NATIONAL LEVEL.

MISSOURI IS A NATIONAL LEADER IN THE FIELD OF ALZHEIMER'S RESEARCH. WE HAVE EXCELLENT MEDICAL, PROFESSIONAL AND VOLUNTEER GROUPS WORKING TOWARD A CURE, AND I HOPE TO HELP BRING THESE GROUPS TOGETHER IN A UNITED EFFORT TO OVERCOME THIS DISEASE.

EXTENSIVE RESEARCH IS BEING CONDUCTED AT WASHINGTON UNIVERSITY AND ST. LOUIS UNIVERSITY, BOTH IN ST. LOUIS, MISSOURI. DR. LEONARD BERG'S "MEMORY AND AGING PROJECT" AT THE WASHINGTON UNIVERSITY SCHOOL OF MEDICINE IS A NATIONALLY NOTED RESEARCH STUDY. LAST OCTOBER, HIS PROJECT WAS CHOSEN AS ONE OF FIVE NEWLY DESIGNATED ALZHEIMER'S DISEASE RESEARCH CENTERS IN THE COUNTRY.

MISSOURI WILL HOST ITS FOURTH ANNUAL "CONFERENCE ON ALZHEIMER'S AND OTHER DEMENTIA" IN APRIL, 1986. THIS CONFERENCE IS DESIGNED TO ADDRESS THE COGNITIVE -- AS WELL AS THE AFFECTIVE AND BEHAVIORAL DOMAINS -- RELEVANT TO THE MANAGEMENT OF ALZHEIMER'S PATIENTS.

RECENTLY, CHANGES WERE MADE IN MISSOURI'S INNOVATIVE OLDER VOLUNTEER SERVICE BANK PROGRAM -- WHICH PROVIDES FUTURE CREDIT TO CAREGIVERS FOR RESPITE PROVIDED TO NEEDY SENIOR CITIZENS -- TO GIVE 1½ HOUR CREDIT FOR EVERY HOUR OF RESPITE CARE GIVEN TO

ALZHEIMER'S PATIENTS. WE RECOGNIZE THE IMPORTANCE OF RESPITE CARE FOR ALZHEIMER'S VICTIMS, AND I COMMEND THE SPECIAL MENTION OF THIS ASPECT OF CAREGIVING IN THE ALZHEIMER'S ACT OF 1985.

WE WILL CONTINUE THE BATTLE AGAINST ALZHEIMER'S DISEASE IN MISSOURI. THE "COMPREHENSIVE ALZHEIMER'S ASSISTANCE, RESEARCH AND EDUCATION ACT OF 1985" WOULD BE BENEFICIAL TO OUR EFFORTS IN TWO WAYS: IT WOULD ENHANCE THE GROWING RECOGNITION AND ACCEPTANCE OF ALZHEIMER'S DISEASE AS A NATIONAL CONCERN; AND IT WOULD PROVIDE RESOURCES AT THE STATE LEVEL TO EXPAND THE NETWORK OF FAMILY SUPPORT GROUPS.

I THANK THE COMMITTEE FOR ALLOWING ME TO TESTIFY ON H.R. 2280. ON BEHALF OF 61,980 MISSOURIANS, I ENCOURAGE YOUR FAVORABLE CONSIDERATION OF THIS BILL.